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## Communication During First-Time Multidisciplinary Clinic Visits: Navigating Parental Decision Making and Uncertainty Management in Pediatric Chronic Illness

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COMMUNICATION DURING FIRST-TIME MULTIDISCIPLINARY CLINIC  
VISITS: NAVIGATING PARENTAL DECISION MAKING AND UNCERTAINTY  
MANAGEMENT IN PEDIATRIC CHRONIC ILLNESS

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
College of Communication and Information  
at the University of Kentucky

By:  
Anna M. Kerr

Lexington, Kentucky

Co-Directors: Dr. Nancy Grant Harrington, Professor of Communication  
Dr. Allison M. Scott, Assistant Professor of Communication

Lexington, Kentucky

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## ABSTRACT OF DISSERTATION

### COMMUNICATION DURING FIRST-TIME MULTIDISCIPLINARY CLINIC VISITS: NAVIGATING PARENTAL DECISION MAKING AND UNCERTAINTY MANAGEMENT IN PEDIATRIC CHRONIC ILLNESS

Individuals with chronic illnesses must manage long-term uncertainty and decision making as they cope with the ways the illness influences almost every aspect of their lives. In the context of pediatric illnesses, parents assume the burden of uncertainty management and decision making during the diagnosis and treatment of their child's illness. It is common for children with complex chronic illnesses to see multiple specialists for the treatment of their condition. The first visit to a specialist is often more elaborate than a routine primary care visit. While previous research has explored parents' decision making and uncertainty management during a child's diagnosis and during end-of-life care, less is known about these experiences during the long-term management of a chronic illness through the care of multiple specialists. The aim of the current study was to explore uncertainty and decision making during parents' first visit to a multidisciplinary clinic for the care of their child's complex chronic illness. Data were collected through survey measures and semi-structured interviews with 30 parents after their first visit to a vascular anomaly clinic at a large Midwestern children's hospital. The results suggest parents' communication with the team of specialists helps them reappraise uncertainty, engage in effective uncertainty management, and feel validated in their decision making. However, the findings also indicate that parents face multiple uncertainty management dilemmas, including not wanting certain types of information, feeling overwhelmed by the amount of information they receive, and having different information preferences than their spouses. Ultimately, the results also have important implications for existing uncertainty theories and their application to parents' uncertainty experiences.

**KEYWORDS:** Multidisciplinary Care, Uncertainty Management, Decision Making, Pediatric Chronic Illness, Communication

Anna M. Kerr  
Student's Signature

April 22, 2014  
Date

COMMUNICATION DURING FIRST-TIME MULTIDISCIPLINARY CLINIC  
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## **Chapter One: Introduction**

Individuals living with chronic illnesses must learn to manage the ways the illness influences most areas of their lives, including daily activities, social relationships, and their personal identity (Corbin & Strauss, 1987). When individuals are diagnosed with a chronic illness, their perceptions of who they were in the past and who they hope to be in the future are often “rendered discontinuous” with who they are in the present (Corbin & Strauss, 1987, p. 249). Although chronic illnesses can become stable over time, even the smallest disruption can cause them to destabilize. The continual changes in disease trajectory increase the amount of illness management required and create a dynamic context for uncertainty (Corbin & Strauss, 1985).

Uncertainty occurs “when information is unavailable or inconsistent and when people feel insecure about their own state of knowledge or the state of knowledge in general” (Brashers, 2001, p. 478). Living with a chronic illness can give rise to a great deal of uncertainty. Mishel (1988) suggests that situations are uncertain when individuals lack the cognitive schema needed to classify the situation accurately and respond accordingly. The uncertainty stems from the ambiguous, unpredictable, unknown, and complex nature of illnesses. Recently, uncertainty scholars have also acknowledged personal and social sources of uncertainty, such as the fear of rejection or social isolation that often accompany chronic illness (Brashers, Neidig, Reynolds, & Haas, 1998; Brashers et al., 2003).

In contrast to individuals with acute illnesses, who typically manage uncertainty by focusing on recovery, individuals with chronic illnesses must learn to accept long-term uncertainty (Mishel, 1999). Living with a chronic illness introduces the potential for

multiple, interwoven uncertainties (Babrow, 2001; Babrow, Kasch, & Ford, 1998). For example, individuals with chronic illnesses can experience several illness trajectories simultaneously (Corbin & Strauss, 1985), which can entail multiple (and potentially conflicting) treatment options (Brashers et al., 1998). Even when individuals experience improvements in their health, uncertainty can arise from the fear of recurrence, the stress of resuming daily activities, or the burden of trying to reestablish interpersonal relationships affected by the illness (Brashers et al., 1999).

Uncertainty can be even more complex for parents of children diagnosed with a complex chronic illness. Each year, the number of children and adolescents living with chronic health problems increases (Halfon & Newacheck, 2010; Perrin, Bloom, & Gortmaker, 2007). According to a variety of national surveys, approximately 12.8% to 17.6% of children live with special health care needs requiring medical treatments that exceed routine care (Bethell, Read, Blumberg, & Newacheck, 2008). The Centers for Disease Control and Prevention (2011) suggest that approximately 1 in 3 children is born with a birth defect, which often requires lifelong management. Chronic illness in children is typically the result of congenital abnormalities, neonatal exposures, or unintentional injuries (Halfon & Newacheck, 2010). When diagnosed early, children must learn to live with the limitations imposed by their chronic illness.

The prevalence of chronic illness in children not only affects the children but also their parents. When their child receives a chronic illness diagnosis, parents go through a stage of transition to living with childhood illness (Clarke-Steffen, 1997). This transition is a time of heightened uncertainty for parents because they want a better understanding of their child's future (Clarke-Steffen, 1993). Parents' taken-for-granted assumptions

about the world are disrupted, leading to interruptions in routines and relationships. Consequently, it is common for parents to feel helpless and become overwhelmed with thoughts of their child's possible death (Cohen, 1993b).

The uncertainty that parents experience also influences their ability to make decisions about their child's medical care. Parents face many difficult decisions after their child receives a chronic illness diagnosis (Clarke-Steffen, 1993). However, parents frequently must make important decisions with complex, incomplete, or conflicting information. Uncertainty and decision-making challenges are particularly abundant for parents of children with complex or unknown chronic conditions requiring the care of specialists. For example, parents of children with vascular anomalies (i.e., birthmarks) repeatedly receive inconsistent or incorrect information from physicians because the chronic condition is unfamiliar, symptomatically inconsistent, and complex in etiology (Donnelly, Adams, & Bisset, 2000; Mathes, Haggstrom, Dowd, Hoffman, & Frieden, 2004). The management and treatment of vascular anomalies requires the coordination of multiple specialists from a variety of disciplines (Richter & Friedman, 2012). However, little is known about how parents manage uncertainty when navigating multidisciplinary care.

Multidisciplinary health care teams are essential in the diagnosis and treatment of complex chronic illnesses such as vascular anomalies. The collaboration of multiple specialists is associated with better coordination of patient care and improved health outcomes (Ellingson, 2008). Additionally, the "one-stop shopping approach" of multidisciplinary teams reduces the frustration associated with multiple appointments with different specialists for the same condition (Makary, 2011, p. 2105). Ideally, the

team of specialists can engage in shared decision making and present parents with a mutual decision in one visit. However, the potential for conflicting opinions among specialists may lead to parents receiving inconsistent information (Katz, 1984). When specialists lack a shared diagnostic vision, it can compromise patient-centered care and decision making (Lamb et al., 2013). Therefore, it is important to examine how communication with multidisciplinary specialists influences parents' uncertainty management and decision making.

The goal of the current study is to explore parental uncertainty and decision making by examining parents' communication with specialists during their first visit to a multidisciplinary clinic for the management of their child's chronic illness. In the second chapter, I review extant research on health-related parental uncertainty, decision making, and vascular anomalies, as well as theories on uncertainty and decision making. I also present four research questions guiding my investigation. In Chapter 3, I describe the participants in the current sample as well as the data collection and analysis procedures I used. Next, I present the results of the data analysis by addressing each research question in Chapter 4. Lastly, in the fifth chapter, I discuss the results of the study by identifying the theoretical and practical implications for parental decision making and uncertainty management.

## **Chapter Two: Literature Review**

A variety of historical, social, contextual, and personal factors affect parental uncertainty and decision making in the context of pediatric chronic illness. In this chapter, I review the current literature to identify areas for further exploration. First, I provide an overview of the context of parents' decision making and uncertainty in pediatric chronic illness. Next, I explore the multiple uncertainties associated with care for children with complex chronic illnesses such as vascular anomalies. I also describe the context for the current study by identifying the unique challenges inherent to multidisciplinary care. Finally, I provide an overview of the theoretical frameworks of uncertainty in illness, uncertainty management, and shared decision making and describe the research questions that guided my investigation.

### **Parents and Pediatric Chronic Illness**

Prompted by the shift to a consumer-based health care system, collaborative decision making is increasingly more important to patients and their families. The Patient Self-Determination Act (PSDA) of 1990 protects patient autonomy by giving patients the right to refuse or to consent to medical treatments (Patient Self Determination Act of 1990, 1991). Patients' autonomy is compromised when they are not capable of communicating or making educated decisions (Beauchamp & Childress, 2001). Accordingly, they must rely on a surrogate to make decisions on their behalf. When sick children are too young or too ill to make medical decisions, the surrogate is typically one or both parents. Traditionally, family members are considered to be most capable of knowing patients' preferences because of their intimate knowledge of patients' values and views of health care (Emanuel & Emanuel, 1992). However, according to the



American Academy of Pediatrics (Committee on Bioethics, 1995), the “best interest” standard is difficult to define against the backdrop of many social, cultural, religious, and philosophic debates regarding the care of children. The ambiguity surrounding what constitutes “best interest” increases parental illness uncertainty and complicates medical decision making, especially when the child first receives a chronic illness diagnosis.

The ways parents respond to their child’s chronic illness diagnosis varies widely (Knafl, Breitmayer, Gallo, & Zoeller, 1996). Some parents adopt a “thriving” management style, being proactive to ensure the illness is not a burden for their child. These parents usually feel confident managing the illness and assume a “life goes on” mentality, characterized by not dwelling on the child’s illness. Parents who adopt an “accommodating” or “enduring” management style are more aware of the negative consequences of their child’s illness. Their preoccupation can force them to neglect other aspects of their own lives, such as their career (Clarke-Steffen, 1993). Concerns about the future influence their communication about their child’s illness, and their parenting techniques can be over-protective (Knafl et al., 1996). These parents tend to express that they are doing the best they can despite the circumstances.

Some parents react to their child’s illness with more detrimental management styles that exhibit struggle or despair (Knafl et al., 1996). These parents dwell on the negative influence the child’s illness has on the family. The children of these parents are more likely to dwell on the ways the illness interferes with their ability to live a “normal” life. In extreme cases, parents view the illness as a “hateful restriction” that causes problems for the entire family (Knafl et al., 1996, p. 321). These parents often express

frustration with parenting, disease management, and quality of life, frequently leading to poor treatment adherence and poor management of the illness.

Overall, when a child is born with a chronic illness, parents can become preoccupied with thoughts about the future for their child. Although some parents refuse to dwell on their child's illness, others feel burdened by the illness and its influence on their ability to live a normal life (Knafl et al., 1996). Regardless of their management approach, almost all parents experience uncertainty about their child's future because of the illness.

**Parental Illness Uncertainty.** Parents of children with chronic illnesses often experience heightened feelings of uncertainty. From the time parents recognize something may be wrong with their child to the point of reaching a formal diagnosis, parents experience intense uncertainty (Stewart & Mishel, 2000). This phase of "waiting and not knowing" is accompanied by feelings of uncertainty, vulnerability, and worry (Clarke-Steffen, 1993, p. 146). During this time, children may see multiple health care providers or consult disease-specific specialists for their complex condition (Forrest, Majeed, Weiner, Carroll, & Bindman, 2003). The initial visit to a specialist can be much more involved than routine medical visits (Graugaard, Holdersen, Eide, & Finset, 2005). The child may undergo numerous diagnostic tests, requiring parents to place a great deal of trust in physicians to make decisions and relay information about their child's treatment (Clarke-Steffen, 1993). However, parents sometimes receive only pieces of information about test results, making the diagnostic picture unclear (Clarke-Steffen, 1993). This uncertainty often reduces parents' abilities to plan for both the short-term future (e.g., medical appointments) and the long-term future (e.g., life expectancy).

In addition to partial information, parents often receive conflicting information from multiple sources during their child's diagnosis process (Clarke-Steffen, 1993). For example, the child's primary care physician may provide information that contradicts the recommendations of a specialist. This contradiction can cause parents to assume the worst until a diagnosis and treatment plan are made clear. Long periods of diagnostic uncertainty can also cause parents to experience particularly high levels of stress. A clear diagnosis, regardless of the severity of the condition, often helps alleviate parents' stress about their child's future (Cohen, 1993b). However, a diagnosis does not eliminate all sources of uncertainty. Receiving a diagnosis sometimes broadens the scope of parents' uncertainty from the unknown nature of the illness itself to encompassing all aspects of the child's and parent's lives (Cohen, 1993a).

After their child receives a diagnosis, parents experience multiple interwoven uncertainties. Initially, parents can experience existential uncertainty, or concerns about their child's chance of survival and overall quality of life (Cohen, 1993a). This uncertainty typically manifests in intense periods of information management during which parents gather and process information from health care providers, family members, and printed materials, in addition to observing their child's physical symptoms (Clarke-Steffen, 1997). Parents often encounter challenges while seeking information, including complicated technical language, unclear responses from physicians, and probabilistic survival rates (Clarke-Steffen, 1997; Cohen, 1993b). Processing the information requires parents to take multiple pieces of information and synthesize them into a meaningful whole to make decisions, which can be a difficult task.

In addition to uncertainty about their child's future, parents also experience uncertainty related to the cause of the child's illness (Cohen, 1993a). This etiological uncertainty stems from parents' desires to know why *their* child has this condition. When a causal link is not clear, parents may experience feelings of guilt or defenselessness. They often continue to search for explanations even after their health care providers reassure them that the cause of the child's condition is unknown (Bearison, Sadow, Granowetter, & Winkel, 1993). The inability to determine a cause of the illness is coupled with uncertainty that stems from the inability to predict the trajectory of their child's illness. When a child has periods of illness activity and stability, parents experience uncertainty because of unpredictable symptom patterns or illness trajectory cues (Stewart & Mishel, 2000). Even a lack of symptoms can cause uncertainty when parents fear the recurrence of the disease (Hinds et al., 1996).

Another form of uncertainty parents may experience is uncertainty from the pressure to make decisions with insufficient information, often during times of emotional stress and urgency. Many parents have no previous experience in hospitals and have limited knowledge of the health care system (Mishel, 1981; Stewart & Mishel, 2000). What is routine for providers is often an emotional crisis for patients and families (Cegala, McNeilis, McGee, & Jonas, 1995). Parents' uncertainty about the unknown nature of the health care system can lead to high levels of uncertainty about health care providers' competence and capacity to care for their child (Turner, Tomlinson, & Harbaugh, 1990), especially if parents feel as though the medical system is working against them (Clarke & Fletcher, 2005). Some parents respond to the complex medical system by becoming an advocate for their child's health care (Clarke & Fletcher, 2005).

They focus on ensuring that their child receives the best care possible. However, for some parents, the uncertainty associated with the medical system makes them feel as if they need to be overly vigilant of their child, which can compromise their ability to care for their child (and themselves) effectively (Turner et al., 1990).

The last form of uncertainty experienced by parents is biographical uncertainty, or uncertainty about the effects of the child's illness on parents' identities and roles (Cohen, 1993a). Parents can feel internally conflicted by simultaneously acting as a caregiver and a tormentor of their child when administering unwanted or uncomfortable treatments. Additionally, parents frequently modify their professional roles to meet the demands of the child's illness (Clarke-Steffen, 1997), including taking time off from work to be available to care for the child or working overtime to manage the uncertain financial future. The uncertainty of caring for a sick child can also have negative effects on interpersonal relationships. For example, some parents report disagreements with their spouse about the care of the child or an unfair imbalance in caretaking responsibilities (Knafl et al., 1996).

In summary, parental uncertainty acts as a secondary chronic condition that is dependent on, and situated within, the primary chronic condition, which is the child's illness (Cohen, 1995). Previous research suggests that health care providers can help parents manage illness uncertainty by providing sufficient explanations of the causes and consequences of the disease symptoms, offering information about the illness and the health care system, and creating congruity between what is expected and what is experienced during the illness trajectory (Mishel, 1988). However, parents commonly feel as though their health care providers do not sufficiently acknowledge the uncertainty

associated with the diagnosis (Clarke-Steffen, 1993). Uncertainty stemming from conversations with health care providers can complicate parents' abilities to make urgent health care decisions for their child (Stewart & Mishel, 2000). While a clear diagnosis gives health care providers a better understanding of the appropriate treatments and course of the illness, parents generally lack the specialized knowledge that helps guide medical decision making.

**Parental Decision Making.** When parents act as surrogate decision makers for their child, the primary goal of communication with providers is reaching agreement about treatment (Curtis et al., 2001). Ultimately, decision making involves two primary elements: (a) information processing, which includes disclosure, sense making, and expectations, and (b) relationship building, which encompasses emotional support, trust, conflict, and roles (Torke, Petronio, Sachs, Helft, & Purnell, 2012). During their child's diagnosis period, parents must quickly process complex medical information that is inherently ambiguous and probabilistic to make decisions (Cohen, 1993b). When parents are uncertain about the outcomes, they can feel forced to make a decision with no clear favorable alternative, and they may have difficulty discerning what option is in the best interest of their child.

While there is no clear definition of a good decision (Rimer, Briss, Zeller, Chan, & Woolf, 2004), an effective decision is typically reached through informed and shared decision making. Informed decision making requires more than obtaining written or verbal consent (Whitney, McGuire, & McCullough, 2004); it entails obtaining a comprehensive understanding of each option and the associated risks and benefits (Rimer et al., 2004). Parents must also take into consideration their own personal preferences and

feel satisfied with the extent to which they participate in decision making. To accomplish shared decision making, parents and providers must engage in a process of exchanging ideas and collaborating on the final decision (Whitney et al., 2004). This requires providers to identify all possible treatment options and allows parents to express their personal preferences and values to make a shared decision.

Shared decision making is particularly important for highly uncertain decisions, regardless of their level of risk (Whitney et al., 2004). Decision making is influenced when health care providers have diagnostic uncertainty about a particular illness. While revealing diagnostic uncertainty can further complicate decision making (Quill & Suchman, 1993), some research suggests that the disclosure of medical uncertainty is an important part of providing patients and their families with the information needed to make an informed decision (Henry, 2006). Communicating uncertainty to parents can actually help to increase their certainty about outcomes discovered collaboratively through shared decision making (Politi, Han, & Col, 2007). However, physicians frequently fail to discuss their uncertainties about the course of care (Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999). Although choosing not to disclose uncertainty may be an attempt by the provider to help facilitate decision making, it can confuse the parent even more by preventing them from differentiating between possible choices (Politi et al., 2007; Politi & Street, 2011).

When decisions are uncertain, decision making is complicated by misunderstandings about the prognosis of the patient (Step & Ray, 2011). Previous research suggests that during the early stages of diagnosis, physicians often maintain an acute approach to treatment that focuses on finding a cure rather than managing

symptoms (Step & Ray, 2011). Optimistic communication from physicians can give families a false sense of hope regarding their child's prognosis. Boyd and colleagues (2010) claim that, even with the most effective communication, physicians and parents may view the child's prognosis differently. In fact, in one study (Cherlin et al., 2005), only 24% of caregivers agreed with the physician about how long their child had to live, reporting that they did not feel as though the health care providers clearly explained the seriousness of the child's condition. When discussions about the child's prognosis do not occur early and often, parents often are unprepared for important decisions and possibly the loss of their child.

In addition to illness-related information, parents also rely on their relationship with health care providers when making decisions (Hinds & Kelly, 2010). Parents' relationships with their health care providers can help them feel reassured that they are being a good parent during decision making. Hinds and colleagues (2009) discovered that parents who believed they were a good parent at the end of their child's life were better prepared to cope with the emotional devastation of losing a child. Parents in their study reported that being a good parent meant being there for the child, maintaining faith, and not allowing their child to suffer if getting healthy was not an option. Being a good parent also involves overcoming personal feelings of stress or sadness to focus on being an advocate for their child during difficult times (Clarke & Fletcher, 2005). However, during end-of-life care, parents often want confirmation that they have exhausted all reasonable possibilities for saving their child before refusing additional treatment (Hinds et al., 1997). Parents may experience extreme feelings of guilt and selfishness if they believe they have prematurely eliminated their child's last possible hope for survival (Sharman,



Meert, & Sarnaik, 2005). Therefore, to address uncertainty about making good decisions, parents often request information implicitly by relying on the relationship they have established with their health care providers (Hinds & Kelly, 2010). For example, parents may ask physicians, “What would you do if this were your child?” This question is not only a request for information regarding the child’s prognosis but also confirmation of the trust and respect the parent has for the physician as a health care provider and a trusted decision-making partner. This request also helps parents to confirm that they are being a “good parent” to their child.

In summary, decision making can be challenging for parents of children with chronic illnesses when they are faced with complex illness information that is ambiguous and uncertain (Cohen, 1993b). Previous research suggests that health care providers are the most trusted source of illness-related information (Hesse et al., 2005). Parents and health care providers must engage in both information processing and relationship building to make a decision that is in the best interest of the patient (Torke et al., 2012). A process of informed and shared decision making is ideal when making treatment decisions for uncertain or high-risk decisions (Whitney et al., 2004). Therefore, the relationship parents have with health care providers is especially important when making decisions about the treatment of complex chronic conditions, such as vascular anomalies.

### **Vascular Anomalies**

Parental uncertainty is prevalent in the medical care for children born with vascular anomalies, commonly known as “birthmarks.” Most vascular anomalies are present at birth and manifest as visible imperfections of the skin and soft tissue due to congenital abnormalities in vascular development (Buckmiller, Richter, & Suen, 2010).

There are two primary types of vascular anomalies: vascular tumors and vascular malformations (Enjolras, Wassef, & Chapot, 2007). Vascular tumors are tumors caused by cellular overgrowth. The most common form of vascular tumor is the infantile hemangioma, which typically goes away during childhood. Infantile hemangiomas are more prevalent in female patients. Vascular malformations are defects in the development of the vascular system and are classified by the low or high flow of the veins. Vascular malformations include capillary malformations, venous malformations, lymphatic malformations, and arteriovenous malformations. These malformations occur equally in males and females and typically continue to develop as the patient grows (Enjolras et al., 2007).

Many vascular anomalies are invasive and are complicated by additional health concerns. For example, many vascular anomalies affect major organs including the eyes, brain, liver, intestines, and spine (Vascular Birthmark Foundation, 2011). Additionally, many venous malformations are associated with syndromes that can cause additional health problems. Some classifications of malformations are associated with Klippel-Trénaunay Syndrome, which is characterized by progressive overgrowth of an extremity (Enjolras et al., 2007). Managing these complex vascular anomalies requires the coordinated care of multiple specialists over several years or even a lifetime. If left untreated, some of the most complex vascular anomalies can cause seizures, blood clots, limb length discrepancies, soft tissue hypertrophy, and intellectual deficiencies (Patel & Curry, 2010).

The treatment of complex vascular anomalies does not belong to any one medical specialty and is frequently unfamiliar to primary care physicians. As a result, many

children with vascular anomalies are misdiagnosed and receive an unclear diagnosis (Mathes et al., 2004) or, worse, an incorrect diagnosis that can lead to ineffective and potentially harmful treatment (Burrows, Tal Laor, & Robertson, 1998). The terminology used to diagnose and describe vascular anomalies has been inconsistent over the years (Rieu & Festen, 1996) because of the rarity of the condition and the numerous classifications of the condition (Donnelly et al., 2000). For example, the term “hemangioma” is frequently used incorrectly by researchers and providers to refer to all classifications of vascular anomalies. A recent meta-analysis (Hassanein, Mulliken, Fishman, & Greene, 2011) revealed that approximately 70% of articles with the word “hemangioma” in the title incorrectly used the term. Similarly, in 2010 an estimated 60% of vascular anomalies were misdiagnosed (Patel & Curry, 2010). The unknown etiology of vascular anomalies leads to situations of complex, contradictory, and incomplete information.

Overall, caring for vascular anomalies is a complex process requiring the coordination of multiple specialists. There are both medical and surgical treatments available for vascular anomalies, including steroid treatment, surgical excision, sclerotherapy, and laser treatment (Richter & Friedman, 2012). In some cases, no single treatment is favored over others, so multiple treatments are needed to manage the vascular anomaly. As a result, pediatricians frequently refer children with vascular anomalies to a multidisciplinary health care team (Richter & Friedman, 2012). Multidisciplinary health care allows for collective decision making among a team of experts and can result in quicker diagnosis and treatment of health care conditions such as vascular anomalies (Makary, 2011).

## **Multidisciplinary Health Care**

When the need for medical specialists increases, so does the need for multidisciplinary teams to diagnose and treat patients with complex conditions (Cooley, 1994; Cott, 1998). In the United States, approximately 20% of pediatric patients are referred to a specialist each year (Forrest et al., 2003), and nearly 8% of those referrals are to a team of specialists coordinating multidisciplinary care. A health care team is “an intact group of health care providers motivated to communicate with each other regarding the care of specific patients” (Real & Poole, 2011, p. 101). Therefore, a multidisciplinary team includes specialists from different disciplines who work together to coordinate patient care but perform their duties autonomously within their respective specialties (see Poole & Real, 2003). When teams communicate effectively, patients receive the benefits of multiple specialties without compromising the continuity and stability of primary care (Wagner, 2000).

The use of collaborative decision making by multiple specialists can have many benefits, including better coordination of patient care, improved health outcomes, decreased hospital stays, and decreased mortality (see Ellingson, 2008). The goals of most multidisciplinary team meetings include providing good patient care, making shared decisions, and coordinating care by creating a joint treatment plan (Fiorelli, 1988). Even once they reach a shared decision, it is important for team members to continue to communicate with each other to eliminate redundancies and prevent gaps in patient care. Previous research suggests that effective health care teams have a well-defined purpose, shared leadership, regular communication and documentation of patient-related information, cohesiveness (fostered through participation in team tasks), and mutual

respect for the contributions of each person, personally and professionally (Mickan & Rodger, 2005). Patient-centeredness in decision making is also important for multidisciplinary teams to ensure all members of the team are focused on the well-being of the patient (Lamb et al., 2013).

Despite the benefits of multidisciplinary care, there are also challenges that constrain the effectiveness of multidisciplinary teams. Multidisciplinary health care teams must engage in frequent negotiation of roles, power, and conflict (Poole & Real, 2003). Effective negotiation is especially important when the health care is complex and uncertain. One challenge to effective negotiation stems from the diverse opinions of specialists from different disciplines, which can prevent good communication within the team and with patients. Specialists may have a limited diagnostic vision and a belief that treatments rooted in their own specialty are more effective than others (Katz, 1984). If parents receive contradictory information from specialists, it can increase their feelings of uncertainty and challenge their decision-making abilities. Additionally, if specialists' narrow diagnostic visions result in a lack of shared goals, it can compromise patient-centered care and decision making (Lamb et al., 2013; Shaw, De Lusignan, & Rowlands, 2005).

Another challenge to effective multidisciplinary health care is effectively coordinating communication among the team members and the referring primary care providers. Communication in multidisciplinary teams frequently occurs “backstage,” with one provider or nurse providing the patient with a final diagnosis or treatment recommendations (Ellingson, 2008). When patients receive only one final recommendation, it contributes to an “illusion of certainty” (Quill & Suchman, 1993) that

providers often try to maintain during conversations. This illusion of certainty challenges the fundamental purposes of informed and shared decision making achieved through collaboration between providers and parents. Another challenge of multidisciplinary care is coordinating care between the child's primary care provider and the team of specialists. One study (Stille, McLaughlin, Primach, Mazor, & Wasserman, 2006) found that only 50% of initial referrals included communication from the referring physician to the specialist. The specialists reported that the lack of communication from primary care providers before the consultation makes it difficult to provide patients with the best care possible.

In summary, multidisciplinary health care is becoming more prevalent in the management of complex chronic conditions (Cooley, 1994; Cott, 1998). Multidisciplinary care allows patients to see multiple specialists without making numerous appointments (Wagner, 2000). Therefore, a primary benefit of multidisciplinary care is the ability to make shared decisions during one visit (Fiorelli, 1988). However, the potential for conflict among specialists who have different diagnostic visions or who lack shared goals can lead to increased uncertainty and decision-making challenges (Katz, 1984; Lamb et al., 2013; Shaw et al., 2005). Therefore, it is important to examine how parents manage uncertainty and decision making associated with multidisciplinary care.

### **Theoretical Frameworks**

The review of previous literature highlights the uncertainty and decision making challenges associated with caring for a child with a chronic illness. Parents experience heightened feelings of uncertainty when their child receives a chronic illness diagnosis

(Stewart & Mishel, 2000). Uncertainty also increases when parents are seeking a clearer diagnosis or are consulting multiple providers for the management of their child's condition (Clarke-Steffen, 1993; Forrest et al., 2003). Two extant theoretical frameworks help explain parents' management of uncertainty. In the next section, I provide an overview of Mishel's (1988) theory of uncertainty in illness and Brashers and colleagues' (2000) uncertainty management theory.

For several decades, communication scholars relied on the assumption that uncertainty is an unwanted experience individuals want to reduce. Uncertainty reduction theory (Berger & Calabrese, 1975) suggests that as we become more uncertain, we become less confident in our abilities to predict or understand future interactions, which results in an overwhelming desire to seek information that will reduce uncertainty. More recently, communication scholars have broadened this theoretical scope and suggested that information seeking is only one possible response to uncertain situations (Brashers & Babrow, 1996). The theory of uncertainty in illness (Mishel, 1988) and uncertainty management theory (Brashers et al., 2000) both explore how people manage uncertainty based on their appraisal of the uncertainty.

**Theory of Uncertainty in Illness.** Mishel's (1988) theory of uncertainty in illness describes how patients cognitively interpret illness-related events. The theory has four primary components: (a) antecedents of uncertainty, (b) appraisals of uncertainty, (c) uncertainty coping strategies, and (d) adapting to uncertainty. The first component, antecedents of uncertainty, includes stimuli frame, structure providers, and cognitive capacity (Mishel, 1988; Mishel & Braden, 1988). The stimuli frame refers to the illness-related events (i.e., stimuli) that patients interpret to make sense of their experiences and

includes symptom patterns, event familiarity, and event congruency (Mishel, 1988). Essentially, patients experience increased uncertainty when they are unable to make sense of symptoms, when they perceive the health care environment to be novel or complex, and when their expectations are not consistent with actual health-related events. The second antecedent to uncertainty, structure providers, includes the resources available to patients to help make sense of the stimuli frame (Mishel, 1988). Education, credible authority, and social support are the structure providers identified as the most significant in illness experiences. The theory posits that uncertainty increases when patients are less educated, do not perceive their health care providers to be credible, and lack the informational and emotional support needed to cope with illness experiences. Lastly, the third antecedent, cognitive capacity, refers to patients' ability to process illness-related information (Mishel, 1988). Patients with reduced cognitive capacity experience increased uncertainty because they often perceive the health care environment as a danger and are unable to process stimuli effectively.

The second element of Mishel's (1988) theory is the appraisal of uncertainty. The antecedents identified in the theory result in uncertainty when they expose the ambiguous, complex, unknown, and unpredictable nature of the illness. According to the theory, uncertainty is a neutral experience until patients appraise it as either a danger or an opportunity. The concept of uncertainty appraisal stems from Lazarus and Folkman's (1984) stress and coping model, which suggests that individuals appraise potentially stressful situations by evaluating the gravity of the situation and how capable they are of handling the situation. Therefore, uncertainty is not inherently positive or negative, but rather uncertainty leads to positive or negative feelings depending on its relevance to the



individual's life (McCormick, 2002; Mishel, 1988). According to the theory, patients appraise uncertainty as a danger when they perceive negative outcomes or potential harm (e.g., inability to engage in everyday activities), and patients appraise it as an opportunity when it is associated with positive outcomes (e.g., avoiding negative certainty) that allow for hope and optimism (Mishel, 1988).

The appraisal of uncertainty determines how patients cope with uncertainty, which is the third component of Mishel's (1988) theory. When patients appraise uncertainty as a danger, they usually cope by attempting to reduce uncertainty and manage negative emotions. Uncertainty reduction strategies include mobilizing techniques such as information seeking and affect-management techniques such as prayer. Conversely, when patients appraise uncertainty as an opportunity, coping typically involves buffering strategies to maintain or increase uncertainty. For example, patients may avoid new information, such as test results, that reveals negative certainty. By avoiding certain information, patients are able to maintain the sense of hope provided by uncertainty. The last component of the theory of uncertainty in illness (Mishel, 1988) is adaptation to uncertainty. Adaptation occurs when patients' coping strategies are effective in manipulating uncertainty in the desired direction. When patients adjust to uncertainty, they are able to resume "normal" behaviors and engage in goal-oriented activities.

In summary, Mishel's (1988) theory of uncertainty in illness describes how patients cognitively process illness-related events. The theory acknowledges that uncertainty is inherently neutral and describes how patients cope with uncertainty based on their appraisal of uncertainty as positive or negative. Brashers and colleagues' (2000)

extended Mishel's theory of uncertainty by identifying the communication behaviors that are associated with the management of uncertainty.

**Uncertainty Management Theory.** Similar to Mishel's (1988) conceptualization of uncertainty, Brashers' (2001) uncertainty management theory is grounded in the assumptions that uncertainty is not always accompanied by feelings of anxiety (Gudykunst, 1995a, 1995b) and that information seeking does not always reduce uncertainty (Mishel, 1988). According to the theory (Brashers et al., 2000), uncertainty is a neutral cognitive experience that is appraised in terms of the emotions it evokes. Emotional responses triggered by the appraisals of uncertainty prompt the individual to communicate with others to manage uncertainty through information and seeking social support.

When patients appraise uncertainty as a danger, one way they try to reduce uncertainty or manage negative emotions is by managing information (Brashers et al., 2000). Seeking information allows individuals to distinguish between possible options, such as treatments or medications, or determine the meaning of an event, such as mysterious symptoms (Brashers et al., 2000). According to uncertainty management theory (Brashers et al., 2000), patients engage in active, passive, and experiential information seeking to manage uncertainty. Active information seeking refers to direct requests for information from family, friends, and health care providers. Conversely, passive information seeking refers to participation in "information-rich environments" (p. 71), such as social support groups, where information is likely to be circulated without direct information seeking efforts. Lastly, experiential information seeking refers to knowledge that individuals gather through personal experience and self-experimentation

that helps guide the uncertainty management process. Ultimately, individuals engage in any of the three methods of information seeking to find information that will help them create the illusion of coherence and certainty, regardless of whether it is correct (Brashers, 2001).

Individuals who positively appraise uncertainty often communicate with others to maintain or increase feelings of hope (Brashers, 2001). The principles of uncertainty management theory posit that individuals accomplish this goal by either avoiding information to maintain uncertainty or seeking information to increase uncertainty (Brashers et al., 2000). Avoiding information is not just the absence of information seeking; it involves actively ignoring information or regulating conversations to avoid unwanted information (Barbour, Rintamaki, Ramsey, & Brashers, 2012). Avoidance may also include social withdrawal (Brashers, 2001). For example, many individuals avoid attending social support groups to avoid receiving information that makes it difficult to maintain hope for the future (Brashers et al., 2000). Individuals also may avoid information, such as test results, to avoid confirming guaranteed negative outcomes (Barbour et al., 2012). In addition to maintaining uncertainty, some individuals prefer to seek information to increase uncertainty. Gathering more information can help reveal new treatment options or it can challenge existing expectations and therefore increase uncertainty.

In addition to information management, uncertainty management theory identifies social support as tool for managing uncertainty (Brashers et al., 2004). One way supportive others can help individuals manage uncertainty is by assisting them with information management (Brashers et al., 2004). For example, patients with the same

illness can help individuals to seek information, to evaluate information, and to avoid information when needed. Additionally, many individuals find it helpful to have someone to talk to about important issues without judgment, as a way of making issues more concrete or reducing stress. When individuals feel validated and accepted by others, it helps them manage uncertainty more confidently (Brashers et al., 2004) and it reaffirms their relational stability with others (Scott, Martin, Stone, & Brashers, 2011). Support providers can also help patients develop decision-making and self-advocacy skills that are beneficial in coping with their chronic illness (Brashers et al., 2000). Similarly, social support from others can help individuals reappraise uncertainty and normalize illness-related experiences (Brashers et al., 2004; Scott et al., 2011).

Despite the benefits of social support, there are some uncertainty-related challenges associated with seeking and receiving support. In fact, the support provider may actually be a source of unwanted uncertainty (Brashers et al., 2004). For example, it is possible for individuals and support providers to have different support goals (Brashers et al., 2004). When individuals do not want the support they receive, it can be stressful, especially if they worry about how to respond (Scott et al., 2011). Additionally, individuals may feel a loss of control over their own life if they seek social support (Brashers et al., 2004). Individuals may experience an identity-related dilemma when they want assistance but also want to maintain their autonomy (Scott et al., 2011). Another challenge of social support is the group dynamic of peer support. If a member of a peer support group becomes ill or dies, the peer group experience can be more detrimental than supportive (Brashers et al., 2000). For instance, individuals with human immunodeficiency virus (HIV) often lose members of their support system and begin to

fear their own death (Brashers et al. 2004). The challenges associated with social support as a tool for uncertainty management underscore the notion that effective social support must address multiple uncertainties, including informational uncertainty, emotional uncertainty, and relational uncertainty (Scott et al., 2011).

Overall, uncertainty management theory (Brashers et al., 2000) suggests that after appraising uncertainty, individuals rely on communication to manage their uncertainty. Ultimately, communication with others can help individuals manage uncertainty through the management of illness-related information and through the provision of social support (Brashers, 2001). An important facet of both uncertainty theories is the recognition that uncertainty management is not linear and that individuals with chronic illnesses are constantly reappraising multiple uncertainties over the course of the disease trajectory (Brashers et al., 2000; Mishel, 1990). Over time, the uncertainty can shift from anxiety to hope if the individual reframes his or her experience and accepts the uncertainty as a natural part of life (Mishel, 1990; Babrow & Kline, 2000). However, anxiety can turn to fear if new information is potentially harmful or fails to resolve existing unwanted uncertainty (Brashers et al., 2000). Many parents strive to maintain a tolerable level of uncertainty so that they are able to complete daily tasks and not let the uncertainty of their child's illness debilitate them (Siegl & Morse, 1994). Some individuals focus on short-term planning rather than dwelling on the inability to make long-term plans. Others make long-term plans despite the presence of uncertainty, not letting it interfere with their dreams for the future (Brashers, 2001). In either context, parents must learn to manage chronic uncertainty over the course of their child's disease trajectory.

**Communication Model of Shared Decision Making.** Health-related decision making is a dynamic experience that involves a two-way exchange of information and preferences between patients and providers (Siminoff & Step, 2005). Historically, decision making has been considered a logical process that is purposive and goal-directed (Kassirer, 1994). However, scholars recognize that decision making is not always rational and often depends on the choices available, their potential outcomes, and individuals' cognitive abilities (Kahneman & Tversky, 1981). In the context of health-related decision making, different decision and information preferences between providers and patients can also influence what decision is made (see Siminoff & Step, 2005). The communication model of shared decision making (Siminoff & Step, 2005) addresses the non-linear nature of decision making by highlighting the importance of both parties contributing information and preferences to the conversation and underscoring the role communication plays in decision making.

The communication model of shared decision making (Siminoff & Step, 2005) suggests that communication during decision making is more than just an exchange of information; it is a complex social interaction defined by the unique traits and experiences of the decision makers (Siminoff & Step, 2005; Watzlawick, Beavin, & Jackson, 1967). The three primary elements of the model are (a) patient-provider antecedents, (b) communication climate, and (c) treatment decisions (Siminoff & Step, 2005). The first aspect, patient-provider antecedents, refers to the sociodemographic characteristics, the personality traits, and the communication competence the patients and providers bring to the interaction. These antecedents can affect communication between the patient and provider. For example, previous research suggests that physicians spend

more time with well-educated patients (Street, 1992) and that female physicians are more likely to engage in psychosocial communication (Roter, Hall, Aoki, 2002). The next aspect of the model is the communication climate (Siminoff & Step, 2005). The communication climate refers to the situational factors during a medical consultation, including information and decision preferences, role expectations, emotional state, and disease severity. For example, receiving a terminal prognosis during a visit may result in fear or anxiety that influences communication and decision making. Similarly, how much the patient wishes to participate in decision making, their perceptions of the competence of the provider, and the providers' affective communication can shape the communication climate. For instance, whereas most patients want to retain some autonomy, patients with life-threatening conditions may prefer a more passive role in decision making. The last element of the communication model of shared decision making is the treatment decision (Siminoff & Step, 2005), or the outcome of the decision making process. An important contribution of the model is that it acknowledges that a decision is also the starting point for future patient-provider interactions. This is especially true in the long-term management of chronic illnesses.

Ultimately, the communication model of shared decision making (Siminoff & Step, 2005) addresses the limitations of previous decision making models that were too linear. The model underscores the importance of abandoning the notion that there is one "right" process for decision making. Rather, decision making is most effective when it is collaborative and involves an exchange of information and preferences to reach the best decision for the patient. The process of shared decision making is especially important in

the context of pediatric multidisciplinary care during which there are more than two parties involved and the communication becomes more complex.

### **Research Questions**

My review of previous research reveals several potential factors that may influence parents' uncertainty and decision making when they visit a multidisciplinary clinic for the diagnosis and treatment of their child's vascular anomaly. Parents are considered to be the best decision makers for their children (Emanuel & Emanuel, 1992), but they face a great deal of unwanted uncertainty and decision making challenges while seeking care for their child. The moment parents realize something may be wrong with their child, they experience multiple uncertainties (Stewart & Mishel, 2000). If parents receive conflicting or incomplete information from multiple sources during the diagnosis process, they often worry about their child's future (Clarke-Steffen, 1993). It can be particularly stressful for parents if they have to make health-related decisions with insufficient information. Parents also experience uncertainty about the cause of their child's illness and their child's chance of survival (Cohen, 1993a). Additionally, many parents experience uncertainty because of their limited knowledge about health care systems (Mishel, 1981; Stewart & Mishel, 2000) and their concerns about their ability to seek care for their child.

Parents of children with vascular anomalies experience additional uncertainty due to the rarity of their child's condition. Many primary care providers lack the knowledge needed to diagnose and treat vascular anomalies (Mathes et al., 2004), so they refer children to a team of specialists that is more familiar with the classification and treatment of vascular anomalies (Makary, 2011). Unfortunately, before their visit to a



multidisciplinary clinic, parents often receive incorrect or incomplete information from their primary care providers who are unfamiliar with vascular anomalies. To improve pediatric multidisciplinary care, it is important to understand parents' uncertainty. Therefore, I pose the first research question to explore parents' uncertainty before their visit:

RQ1: What are the antecedents of uncertainty for parents of children with vascular anomalies before their visit to a multidisciplinary clinic?

Parents of children with vascular anomalies typically experience uncertainty if their primary care provider is unable to diagnose or treat their child's vascular anomaly. Consequently, parents seek care from a team of specialists who are familiar with vascular anomalies. While the collaborative nature of multidisciplinary health care teams can be beneficial (Makary, 2011), the potential for parents to receive conflicting information from specialists with contrasting diagnostic visions can increase parents' uncertainty and compromise decision making (Katz, 1984; Lamb et al., 2013; Quill & Suchman, 1993). Therefore, more research is needed to examine parents' uncertainty and decision making in the context of multidisciplinary care. My next two research questions explore the influence communication with multiple specialists has on parents' uncertainty and decision making:

RQ2: How does parents' communication during multidisciplinary care influence their uncertainty?

RQ3: How do parents describe their health-related decision making during their visit to a multidisciplinary clinic?

When parents experience uncertainty, they manage it through information management and social support (Brashers et al., 2000, 2004). Both the theory of uncertainty in illness (Mishel, 1988) and uncertainty management theory (Brashers et al., 2000) suggest that individuals manage uncertainty based on their appraisal of the uncertainty as either positive or negative. However, we know less about parents' uncertainty management during their first visit to a multidisciplinary clinic where multiple specialists are present. Therefore, I explore the influence of multidisciplinary care on parents' uncertainty management through my next research question:

RQ4: How do parents manage their uncertainty during their visit to a multidisciplinary clinic?

The answers to these questions can help fill the gap in existing uncertainty management and decision making literature. Additionally, the data can shed light on how communication with multiple specialists affects these already complex processes. Overall, my goal for the current study is to examine parental uncertainty and decision making by exploring parents' communication with specialists during their first visit to a multidisciplinary clinic for the management of their child's chronic illness.

### **Chapter Three: Methods**

Managing uncertainty and making decisions is complex, contradictory, and non-linear for parents of sick children. Mishel (1999) has argued that it is most appropriate to use qualitative research methods to capture the unique ebb and flow of uncertainty management in under-studied contexts. Thus, I used in-depth, semi-structured interviews to examine parental uncertainty and decision making in the context of childhood chronic illnesses and multidisciplinary care. Interviewing allowed me to explore themes consistent with previous research but also to discover the unknown as participants revealed that which was most salient in their own experiences (Fontana & Frey, 2000; Lincoln & Guba, 1985). In addition to interviews, I used brief self-report questionnaires to assess participants' perceptions of decision making. Although perceptions are inherently subjective, self-report measures are the most widely used method in the social sciences to test relationships among theoretical constructs (Groves et al., 2009). They are an effective tool for systematically measuring attitudes, beliefs, and values to identify patterns and make predictions (Frey, Botan, & Kreps, 2000). By employing both qualitative and quantitative methods, I had the potential to provide a multifaceted understanding of parents' decision making and uncertainty experiences.

#### **Participants**

Participants for this study include English-speaking parents of children with vascular anomalies. Parents were required to be 18 years of age or older and have at least one child receiving care for a vascular anomaly. Additionally, parents needed to be first-time visitors to a multidisciplinary clinic. I based the decision to choose first-time visitors on research demonstrating that uncertainty is at its highest during the diagnosis process,

and decision making and uncertainty management can be the most stressful during this period (Clarke-Steffen, 1993). Additionally, I chose first-time medical visits because they are unique compared to return visits. They are traditionally longer than return visits to a referred specialist (Graugaard et al., 2005), which provides a rich context for examining decision making and uncertainty.

The current sample was composed of 30 parents visiting a multidisciplinary clinic for the first time. On average, parents had been seeking care for their child's vascular anomaly for 1.05 years ( $SD = 1.87$  years; Range = 0-8.5 years) and had seen an average of two health care providers ( $SD = 1.58$  providers; Range = 0-5 providers) for their child's vascular anomaly before their visit. The average time since diagnosis was 2.18 years ( $SD = 4.44$  years; Range = 0-17 years), with 11 parents receiving their child's first diagnosis at the current visit.

The parent sample included 5 (16.7%) male and 25 (83.3%) female parents. The participants ranged in age from 22 to 49 years old with a mean age of 25.87 years ( $SD = 5.98$  years). The sample was composed of White ( $n = 28$ , 93.3%) and African American ( $n = 2$ , 6.7%) participants. The majority of parents were married ( $n = 28$ , 93.3%); 1 (3.3%) was in a serious relationship, and 1 (3.3%) was divorced. Respondents reported a range of education levels, including a high school degree or general education development (GED) certification ( $n = 13$ , 43.3%), an Associate's degree ( $n = 3$ , 10.0%), a Bachelor's degree ( $n = 9$ , 30.0%), and a graduate degree ( $n = 5$ , 16.6%). Respondents' average yearly household incomes included below \$20,000 ( $n = 1$ , 3.3%), \$20,000 to \$39,999 ( $n = 2$ , 6.7%), \$40,000 to \$59,999 ( $n = 5$ , 16.7%), \$60,000 to \$79,999 ( $n = 5$ ,

16.7%), \$80,000 to \$99,999 ( $n = 5$ , 16.7%), \$100,000 or above ( $n = 10$ , 33.3%); 2 respondents (6.7%) chose not to provide information about their income.

## **Procedures**

Following approval from the Institutional Review Board, I recruited participants from a multidisciplinary vascular anomaly clinic at a large Midwestern children's hospital. I chose this clinic because it has a disease-specific vascular anomaly outpatient clinic that sees approximately 10-12 new patients each week. During clinic visits, patients see multiple specialists from disciplines including hematology, oncology, otolaryngology, dermatology, plastic surgery, radiology, and pediatric surgery. The clinic team also consults with specialists from orthopedics, ophthalmology, cardiology, gastroenterology, neurosurgery, endocrinology, and genetics when necessary. Therefore, the clinic environment adequately captures the complex and multidisciplinary care of children with vascular anomalies.

Over the course of five months, I attended the weekly multidisciplinary clinic sessions to recruit participants verbally and through a recruitment flyer. I displayed the flyer at the clinic registration desks where parents checked in and checked out with the clinic staff for their visit. The flyer contained a brief overview of the study, including the purpose (i.e., to learn how parents manage uncertainty and decision making) and the activities involved in participation (i.e., a short questionnaire and an in-depth, face-to-face interview with a member of the research team). In addition to the flyer, I also verbally recruited parents as they left the clinic. After parents were discharged, they spoke with the clinic administrator who scheduled their follow-up appointment, scheduled laboratory tests, or collected their co-payment. It was during this time that I

provided the parents with information regarding the study and asked if they were interested in participating. At this time, I also addressed any unanswered questions, and if the parents wished to participate, we chose a convenient location near the clinic for the interview (e.g., hospital cafeteria, nearby empty waiting room). Each interview took place after the family's visit with the providers at the clinic to allow parents to reflect on their decision making, uncertainty management, and communication during the entire visit.

If both parents were present for the clinic visit, I asked the parents to decide who preferred to answer questions about their visit. During our meeting, I first obtained informed consent from the parent according to the university human subjects guidelines. The informed consent document outlined the study, the possible risks and benefits, and the voluntary and confidential nature of the participation. After obtaining informed consent, I administered the paper-and-pencil self-report questionnaire. After parents completed the self-report questionnaire, we began the interview. In total, I recruited 31 participants. Approximately 15 parents refused to participate in the study primarily because of other commitments (e.g., needing to return to work or to relieve a babysitter at home). Additionally, after signing the informed consent document, one participant withdrew from the study due to time constraints. Therefore, 30 participants completed the questionnaire and interview. On average, the interviews lasted 14:27 minutes (Range = 6:56 – 23:38 minutes,  $SD = 4:38$  minutes). I intentionally designed my interview protocol to guarantee short interviews to avoid prolonging parents' visits. Using a brief interview protocol also allowed me to stay focused on my four research questions during the interview.

## Data Collection Materials

I collected data using a questionnaire with self-report measures and a semi-structured interview with questions examining parents' communication, decision making, and uncertainty experiences surrounding their child's chronic illness. During data collection, I followed a grounded theory approach by continuing to refine the research questions and the interview protocol to ensure I captured the full range of the participants' experiences and adhered to a participant-directed assessment of what counted as important (Charmaz, 2000).

**Questionnaire.** I used validated measures of decision making to explore parents' experiences (see Appendix A). The four dimensions of decision making I explored were satisfaction, uncertainty, control, and informed choice. I chose to examine decision satisfaction and uncertainty because previous research suggests that parents' decision-making satisfaction and uncertainty are associated with their perceptions of themselves as a "good parent" (Hinds et al., 2009). My literature review also revealed that informed and shared decision making are important in making patient-centered decisions (Siminoff & Step, 2005). Therefore, I chose to examine decision control and informed choice in decision making to explore parents' autonomy and knowledge during the decision making process. After providing a brief overview of their child's medical condition and previously-seen health care providers, parents responded to 16 items from four distinct decision-making subscales while focusing on the *most important decision* they discussed (or made) with the health care providers during their visit (as defined by the participant). All responses were recorded on a 7-point Likert-type scale. I organized the original

reliabilities, reliabilities after deleting items, and mean responses for each subscale in Table 1.



**Table 1. Decision Subscales: Items, Reliabilities, and Means**

Subscales	Original $\alpha$	Modified $\alpha$	Final <sup>**</sup> $M (SD)$
<b>Decision Satisfaction (Holmes-Rovner et al., 1996)</b>			
1. I am satisfied that I am adequately informed about the issues important to my decisions.	.72	-	6.70 (.41)
2. The decisions I made were the best possible decisions for me personally.			
3. I am satisfied that my decisions were consistent with my personal values.			
4. I expect to successfully carry out (or continue to carry out) the decisions I made.			
5. I am satisfied that these were my decisions to make.			
6. I am satisfied with my decisions.			
<b>Decision Uncertainty (O'Connor, 1995)</b>			
7. These decisions will be hard to make.	.61	.70	2.67 (1.79)
8. I'm unsure what to do in these decisions.			
9. It's clear what choices will be best for me. <sup>a*</sup>			
<b>Decision Control (Stalmeier et al., 2005)</b>			
10. These decisions will be made without me. <sup>a*</sup>	.47	.62	6.45 (1.06)
11. I feel pressure from others in making these decisions. <sup>*</sup>			
12. I wish someone else would decide for me. <sup>*</sup>			
<b>Informed Decision (Stalmeier et al., 2005)</b>			
13. I am satisfied with the information I have about these choices. <sup>a</sup>	.53	-	5.20 (2.00)
14. I know the pros and cons of treatment. <sup>a</sup>			
15. I want more information about these decisions. <sup>*</sup>			
16. I want clearer advice. <sup>a*</sup>			

<sup>a</sup> Item deleted to improve subscale reliability

<sup>\*</sup> Item reverse coded for analysis

<sup>\*\*</sup> Calculated after items were deleted

**Decision Satisfaction.** The first six items on the questionnaire represented the satisfaction with decision scale (Holmes-Rovner et al., 1996). Participants indicated how much they agreed with statements about their satisfaction with their decision in relation to their personal values, self-efficacy, and the amount of information they had to make the decision. A higher score represented more satisfaction with decisions made. In the current study, the subscale had a reliability of  $\alpha = .72$ , indicating that the scale had acceptable internal consistency. On average, parents were satisfied with the decisions they made during their visit ( $M = 6.70$ ,  $SD = .41$ ).

**Decision Uncertainty.** The next three items represented decision uncertainty (O'Connor, 1995). Participants indicated how much they agreed with statements about how unsure they were about the decision and whether it was clear what choice was best. A higher score represented more decision uncertainty. The subscale had a low reliability of  $\alpha = .61$  in the present study. The internal consistency of the scale improved to  $\alpha = .70$  when item number nine, "It's clear what choices will be best for me," was removed. It is possible this item reduced the reliability of the subscale because it was the only item reverse coded for analysis. Additionally, the statement may have been difficult for participants to respond to if parents left the visit with a decision to wait until the child was older rather than an immediate treatment decision. Analysis of the modified subscale indicated parents' decision uncertainty was moderately low ( $M = 2.67$ ,  $SD = 1.79$ ).

**Decision Control.** Items 10 through 12 of the questionnaire represented decision control (Stalmeier et al., 2005). Participants indicated how much they agreed with statements about the pressure to make a decision, the desire for someone else to decide for them, or the regret of the decision as a whole. A higher score indicated more decision

control. The three items in the scale were reverse coded, so that a higher score on the scale represented a greater level of decisional control. The subscale had low reliability ( $\alpha = .47$ ) in the current sample. The low internal consistency of the scale slightly improved ( $\alpha = .62$ ) when item number 10, “These decisions will be made without me,” was deleted. It is possible the negative wording of the question influenced responses; however, all three items in the subscale required reverse coding. It is more likely that, because parents were at the clinic with the primary goal of making decisions for their children, the item was not applicable. Ultimately, parents reported high levels of decision control ( $M = 6.45$ ,  $SD = 1.06$ ).

***Informed Decision.*** The final three items represented informed choice in decision making (Stalmeier et al., 2005). Participants indicated how much they agreed with statements about the information they received regarding their decision and the advice they received from the health care providers. The subscale had a low reliability of  $\alpha = .53$  in the current sample. Although deleting one item (“I want clearer advice”) somewhat improved the internal consistency ( $\alpha = .57$ ), the reliability still was not acceptable for data analysis. The lack of internal consistency for this scale may relate to the long-term nature of the decision making for parents in the current sample. Parents who chose a wait-and-see approach were often delaying treatment decisions until future visits to the clinic, so they were generally satisfied with the amount of information they had after their visit. To address informed decision making in the analysis, I chose one item from the subscale that most accurately operationalizes informed decision making, defined as comprehensive understanding of each option and the associated risks and benefits (Rimer et al., 2004). Item number 15, “I want more information,” most closely relates to this

concept of informed decision making in the context of the current investigation. After the item was reverse coded for analysis, parents were relatively satisfied with the information they obtained ( $M = 5.20$ ,  $SD = 2.00$ ). A higher score represented more satisfaction with the amount of information received.

**Interview Protocol.** I developed the interview protocol using the existing literature on parental uncertainty, decision making, uncertainty management, and communication with multidisciplinary teams (see Appendix B). I asked parents to describe the experience of visiting a multidisciplinary clinic, including the health care providers' communication and their own communication as well as their evaluation of the communication. I also asked parents about the decisions they made and what factors were both helpful and hurtful to their decision-making process. Next, I asked parents to explain why the primary decision they made was particularly good or bad and to describe the decision-making process. Finally, I asked parents to explain how they managed uncertainty about their child's health and related decisions, including specific information avoiding and seeking behaviors. I used the semi-structured protocol to guide the interview, but I also asked probing and follow-up questions as needed to clarify or validate participant responses. Additionally, I modified the protocol twice over the course of data collection to follow participants' lead about what experiences were most salient.

During data collection, I paid close attention to experiences described by parents that the interview protocol did not address. Parents' reliance on (and inherent trust in) health care providers during decision making emerged as a significant factor during the first several interviews. Therefore, I added three questions to the protocol to further explore the role of health care providers in decision making and parents' perceptions of

their trust in the providers. The significance of parents' experiences before their visit was also evident after several interviews. I further modified the interview protocol by adding two questions to address communication and information management that occurred before parents' visits. I also noticed that participants were paying particular attention to the dynamics of having multiple providers in the room simultaneously as opposed to each provider one at a time. This prompted me to add four questions exploring parents' perceptions of the communication among specialists, either in the room or outside of the room. Lastly, the potential for diagnostic or treatment uncertainty from the providers was apparent, so I added one question to the interview protocol to explore parents' perceptions of the disclosure of medical uncertainty. The modifications to the interview protocol also prompted adjustments to the research questions.

Consistent with a grounded theory approach (Charmaz, 2000), I modified my research questions as data collection progressed to account for a richer representation of parents' experiences. The four research questions presented in Chapter 2 were the final research questions I used. Initially, I developed eight primary research questions exploring parents' communication, decision making, and uncertainty. The first three original research questions explored parents' communication with the team of specialists, including their satisfaction and specific information management behaviors. The next three explored parents' decision making, including the decisions made during the visit, the process of decision making, and their satisfaction with decisions. The last two questions explored parents' uncertainty and its relationship to decision making and multidisciplinary care. After data collection was complete, I modified the research questions to better represent the parents' experiences. Specifically, I condensed the eight

research questions into four questions focusing on (a) parents' antecedents of uncertainty, (b) the influence multidisciplinary communication has on parents' uncertainty, (c) parents' decision making, and (c) parents' uncertainty management. These final research questions provide a more holistic framework for data analysis.

### **Data Analysis**

After data collection, I transcribed the audio-recorded interviews verbatim (resulting in 205 pages of one-and-a-half spaced text), and analyzed them using a grounded theory approach (Glaser & Strauss, 1967). Specifically, I analyzed the transcripts using latent content (Lincoln & Guba, 1985) and constant comparative techniques (Glaser & Strauss, 1967) with a team of coders. This process allowed me to identify salient themes that emerged from the data and to refine those themes into conceptual categories. I then examined the interrelationships of these conceptual categories to better understand the experiences of the participants.

I, along with two doctoral students with training in communication research, analyzed the 30 interview transcripts. During the initial round of coding, we read the transcripts independently and coded for emergent themes. After the first round of coding, we met to discuss and organize our initial findings. There were many similarities in our salient themes, which allowed us to condense our initial findings into four primary categories. The four categories were (a) unwanted uncertainty before the visit (e.g., unsuccessful online research, unclear diagnosis, etc.), (b) information management during the visit (e.g., decision making, question asking, multiple opinions, etc.), (c) trust in providers during the visit (e.g., inherent credibility, agreement/validation, bedside manner), and (d) coping with uncertainty after the visit (e.g., uncertain future, decision to

wait, medical uncertainty). As we defined these categories, we discovered parents' uncertainty experiences were consistent with Mishel's (1988) conceptualization of the antecedents of uncertainty. Additionally, we recognized that parents' descriptions of communication during the visit were representative of the communication model of shared decision making (Siminoff & Step, 2005). Specifically, the severity of the child's condition, parents' information and decision preferences, and their emotional state were evident during their interviews. Therefore, we used these two theoretical frameworks to inform a categorical coding system that represented parents' uncertainty, communication, and decision making. The categories were (a) antecedents of uncertainty, (b) communication climate (information and decision preferences, disease severity, and relationship building), (c) appraisals of uncertainty, and (d) acceptance of long-term uncertainty.

Before we began the second round of analysis, we randomly selected three (10%) transcripts to code using the system developed during our first meeting. Using electronic communication, we compared our individual coding and resolved any discrepancies before coding the remaining interviews. Specifically, we clarified the conflation of the antecedents of "event familiarity" (which refers to parents' familiarity with and expectations about the health care environment) and "event congruency" (which refers to parents' expectations about the trajectory of their child's illness). We also broadened the original conceptualization of patient-provider communication during the "communication climate" (Siminoff & Step, 2005) to include relational communication, content communication, and multidisciplinary communication in addition to decision preferences, disease severity/emotional state, and role expectations. Once the coding system was

refined, we independently coded all 30 interview transcripts using the refined coding scheme (including the initial three transcripts) to complete the second round of coding.

After the second round of coding, we met again to further clarify the conceptual categories and define the relationships among the categories. After coding for multiple antecedents of uncertainty, we agreed that “symptom patterns” and “credible authorities” (Mishel, 1988) were the two antecedents of uncertainty that significantly influenced parents’ negative appraisal of uncertainty and prompted their strong desire to seek information during their visit. We decided this after recognizing the salience of parents’ frustration with their pediatricians’ unfamiliarity with their child’s symptoms and their relief that the specialists could provide them with accurate information. Similarly, we agreed that parents’ experiences during the visit resulted in a reappraisal of uncertainty primarily influenced by trust (or lack thereof) in the team of specialists. Our primary negotiation focused on the dynamics of the communication during the multidisciplinary care visit. Specifically, while our initial coding system included many dimensions of the communication climate outlined in the communication model of shared decision making (Siminoff & Step, 2005), our further analysis revealed that decision making and information management with multiple specialists were the primary dimensions of the visit. Relational communication (e.g., small talk), multidisciplinary communication (e.g., multiple opinions, consistent information), and illness-related communication (e.g., disease specifics) manifested more clearly as aspects of information management. For example, parents’ preferences for multiple opinions versus one opinion were illustrative of their information management preferences. Once we reached consensus, we read the



interview transcripts in their entirety a third time using the final conceptual coding scheme to confirm that the framework represented each parent's experience.

To further evaluate and confirm the credibility of the conceptual framework, I completed a process of member checking with a subset of parents who participated in the study (Lincoln & Guba, 1985). I randomly selected six parents (20%) from the sample to participate and emailed them an invitation to participate in the voluntary follow-up portion of the study. If parents agreed to participate, I sent them a brief summary of the conceptual framework and the four major findings (Appendix C). If the parents did not wish to participate, I contacted the next parent on the list. I continued this process until six parents provided feedback. Parents' clearly articulated support of the four major findings (Appendix D) reinforced the validity of the data analysis.

After summarizing the results of our conceptual framework, I met with my advisors to discuss the validity of the findings. During this meeting we discovered that parents' experiences were not necessarily representative of the communication model of shared decision making (Siminoff & Step, 2005) but had a stronger conceptual fit with Brashers and colleagues' (2000) uncertainty management theory. The previous conceptual framework based on the communication model of shared decision making provided labels but did not accurately describe the relationship among the categories. Specifically, parents' communication with multiple providers enabled them to engage in information management and receive social support, therefore assisting in their management of uncertainty. Therefore, I used the principles of information management and social support outlined by uncertainty management theory, along with Mishel's (1988) theory of uncertainty in illness, to organize the data into a meaningful narrative

representing parents' uncertainty management and decision making experiences. This change did not significantly alter the major findings of the study, and it resulted in a more cohesive organization of the data to better represent the experiences parents deemed important.

While this approach to data analysis closely follows the traditional, purely inductive grounded theory method, it deviates slightly by recognizing my theoretically-informed position in the investigation. My approach was consistent with Corbin and Strauss' (2008) claim that there are certain benefits to using existing theoretical frameworks to inform data analysis, but it is important for me as the researcher to "remain open to new ideas and concepts" (p. 40). This approach suggests that all inquiry is theory-laden and that theoretical perspectives help shape my perceptions and interpretations of the data (Alvesson & Skoldberg, 2009). However, as a researcher, I must strive to ensure that the emerging categories are defined by the properties of the data collected, and comparisons to previous literature primarily take place after the emerging categories have been identified (Glaser & Strauss, 1967). This process ensures that I do not force the data into fixed categories (Corbin & Strauss, 2008). I, and the two additional coders, adhered to this analytic approach by allowing the data to define the salient themes identified in the initial round of coding before identifying their similarities to existing theories about uncertainty and decision making.

In addition to the qualitative data analysis, I organized the data from the self-report questionnaires using SPSS for quantitative data analysis. After analyzing the qualitative data, I conducted descriptive analyses to provide information about the sample and inferential analyses to further explore the findings. More specifically, I ran two-tailed

correlational analyses to determine whether the responses to the four decision subscales supported the qualitative results. When situated within the qualitative analysis, the results of these statistical analyses provide a further understanding of parents' decision making and uncertainty management when communicating with specialists in a multidisciplinary team.

## Chapter Four: Results

My research questions in this study explored the antecedents of parents' uncertainty (RQ1), how multidisciplinary communication affected parents' uncertainty (RQ2), parents' decision making during their first visit (RQ3), and parents' communicative uncertainty management (RQ4). My analysis of the data revealed symptom patterns and credible authorities were most influential in parents' uncertainty about their child's vascular anomaly. Before their visit, parents appraised uncertainty as a potential danger to their child's future and obtained a referral to a multidisciplinary vascular anomaly clinic to seek more information to reduce uncertainty. Communication with multiple specialists shaped parents' uncertainty by influencing the antecedents of their uncertainty. Communication was also instrumental in parents' decision making and evaluation of their decision satisfaction. Ultimately, parents demonstrated multiple uncertainty management strategies during their first visit to the multidisciplinary clinic, including communicating to manage information and seek social support. I provide an outline of the results in Table 2.

**Table 2. Outline of Results**

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Antecedents of Parents' Uncertainty (RQ1)
Symptom Patterns
Credible Authorities
Multidisciplinary Communication and Uncertainty (RQ2)
Symptom Patterns
Credible Authorities
Multidisciplinary Communication and Decision Making (RQ3)
Benefits of Multidisciplinary Communication in Decision Making
Decision Satisfaction
Multidisciplinary Communication and Uncertainty Management (RQ4)
Information and Uncertainty Management
Social Support and Uncertainty Management

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## **Antecedents of Parents' Uncertainty**

Research Question 1 asked, “What are the antecedents of uncertainty for parents of children with vascular anomalies before their visit to a multidisciplinary clinic?”

Parents experienced unwanted uncertainty due to unfamiliar symptom patterns and a lack of credible authorities. These two antecedents made it difficult for parents to assign meaning to illness-related events.

**Symptom Patterns.** Parents discussed how their child’s symptoms contributed to feelings of uncertainty. When parents were unable to classify and predict their child’s symptoms, they experienced uncertainty. For example, the father of a 7-month-old daughter explained how his expectation that his daughter’s symptoms would decrease over time was not met, which created uncertainty for him and his daughter’s doctor. He explained,

She was in the NICU [neonatal intensive care unit] first and she had tape for the oxygen and so both sides were red from the tape, I guess irritation from the tape. So when we took her home after seven days, the left side went away and the right side remained. We kind of thought at first that it was just a red mark on her face that would go away and it never changed shape; it never changed size or anything. So on her first checkup at two weeks, we told the doctor about it and she had no idea what it was. [Participant 19]

This father’s uncertainty about his daughter’s symptoms illustrated how unpredictable symptoms of vascular anomalies contribute to uncertainty because the parents (and their pediatricians) lacked the knowledge needed to make sense of symptoms.

Indeed, while parents’ uncertainty was often a result of symptom patterns that did not resolve on their own, many parents experienced uncertainty when their child’s symptoms worsened. The mother of a 3-year-old boy described the uncertainty she experienced as her child’s symptoms intensified:

No one really knew. They thought that it was just a birthmark or just a hemangioma. When he was three months, he started having seizures so we saw a neurologist, and the neurologist put the seizures and the malformation together and thought that he had Klippel-Trénaunay Weber Syndrome. [Participant 14]

This mother's experience highlighted how parents experienced uncertainty from worsening symptoms. The lack of a clear symptom pattern also resulted in the mother's receiving multiple diagnoses for her child's condition. In the passage above, the mother described how she received three possible diagnoses: "birthmark," "hemangioma," and "Klippel-Trénaunay Weber Syndrome." Later in the interview, the mother explained that previous providers also used the term "Parks-Webber" to describe the symptoms. Most parents described similar changes in their child's diagnosis, which complicated their understanding of their child's condition. The complicated diagnosis process illustrated how the lack of a clear symptom pattern was a significant antecedent to parents' illness uncertainty before their visit.

The examples above suggested that parents also experienced uncertainty when multiple providers were unfamiliar with their child's symptoms. The father of a 7-month-old girl described the conflicting information he received from providers:

About four, about—let's see what was the most recent appointment, six months, I guess we asked about it again, and they referred us to some dermatologists [in our town]. We went there and the two doctors that saw her both had differing opinions. So, that's always disconcerting. [Participant 19]

As the father described, the rarity of his daughter's symptoms contributed to his uncertainty. When he lacked the specialized knowledge to classify his daughter's symptoms, he turned to health care providers for information. However, like most parents, the providers' inability to help the father make sense of his daughter's symptoms caused him unwanted uncertainty.

**Credible Authorities.** In addition to a lack of clear symptom patterns, the lack of credible authorities was a clear antecedent to parents' uncertainty. Before their visit, many parents realized that their primary care providers were not familiar with the diagnosis and treatment of vascular anomalies. Many parents were referred to specialists by pediatricians who were able to classify the condition as a vascular anomaly but unable to provide a concrete diagnosis or treatment recommendation. For most parents, communication with their child's pediatrician contributed to a lack of trust in the providers and a danger appraisal of uncertainty.

Many parents were not satisfied with their pediatrician's initial recommendations. The mother of a 10-year-old girl explained, "The pediatrician told me not to worry about it; that there's thousands of people with different size limbs. I wasn't really satisfied with that. Wanted a second opinion" [Participant 26]. The pediatrician's dismissiveness reduced the mother's trust and prompted her to seek a second opinion. The mother described how the pediatrician's advice went against her gut feeling that something was wrong with her daughter. Ultimately, her lack of trust in the pediatrician contributed to her appraisal of the uncertain situation as potentially dangerous for her child's health.

While many providers dismissed the unfamiliar conditions, others gave parents incomplete or incorrect information that contributed to uncertainty. The mother of a 2-year-old girl with a vascular malformation described how the pediatric surgeon she visited previously contributed to her uncertainty:

The one thing I guess, if you wanted me to say, that I wish was done a little differently is when we saw the pediatric surgeon the first time, so it's not the same one [...] and a great—she was great, but the one thing she said was—the reason I came in expecting to have to do that one procedure, was she had told me that that's probably what they would have to do. She didn't even tell me that there was a wait-and-see approach. And when—so when we came in here and [the surgeon]

said, “Oh, for something that looks like this, a lot of times we do a wait-and-see approach. We don’t necessarily subject the child to that treatment,” I wish I had known that earlier because I would’ve had a lot less worry. I was trying to figure out how they were going to do injections in a 2-year-old. Would they have to put her to sleep? Would they have to hook her up to an IV? What were we gonna have to do? Would I have to do one or two or three? So I just wish that [the previous doctor] had communicated that there was a wait-and-see approach and that given the size and the area and the fact that it’s not inside any major organs and this and that that they might do that. Even if they didn’t do it, it just would’ve been nice to know that was an option, and that was not told to me that that was an option. [Participant 20]

For this mother, the original pediatric surgeon’s lack of knowledge about the management of vascular anomalies contributed to her uncertainty about the treatment options and general system of care for vascular anomalies. The potential for harmful or unwanted outcomes led to the mother’s negative appraisal of uncertainty.

Parents often recognized that their trusted pediatrician was not always the most reliable authority in the treatment of their child’s vascular anomaly. The mother of a 3-year-old girl with a hemangioma explained that her daughter’s pediatrician was “baffled by the whole thing” [Participant 12]. Although the mother insisted that her daughter’s pediatrician had their best interest in mind, she concluded that the pediatrician was not a credible source of information regarding the treatment of her daughter’s vascular anomaly. The lack of credible authorities during their child’s initial diagnosis phase resulted in high illness uncertainty for many parents.

Overall, Research Question 1 explored the antecedents of parents’ uncertainty before their visit. Communication with previous providers influenced parents’ ability to make sense of symptoms and identify a credible authority. Consequently, parents obtained a referral to a specialist to seek additional information to reduce uncertainty.



## Multidisciplinary Communication and Uncertainty

Research Question 2 asked, “How does parents’ communication during multidisciplinary care influence their uncertainty?” For most parents, the specialists’ communication influenced uncertainty by clarifying previously unclear symptom patterns and revealing new credible authorities for the care of their child’s vascular anomaly. However, the challenges of multidisciplinary care also created more uncertainty for some parents.

**Symptom Patterns.** Parents’ communication with multiple specialists influenced their existing perceptions of their child’s symptoms. For many parents, the specialists were able to help them make sense of their child’s symptoms and give them information about what to expect in the future. The clarification often reduced parents’ uncertainty or made it more tolerable. When asked what contributed to her change in uncertainty, the mother of a 3-year-old boy explained,

Just their reassurance that this does happen sometimes in children his age, because our pediatrician also said that, “This only happens in infants. He shouldn’t be getting it in places like this, that doesn’t happen.” They assured us that it *does* happen, it’s just rare, but now we know that it is a possibility. She [the pediatrician] led us to believe that they couldn’t just be new vascular malformations popping up, which apparently there can be. [Participant 12]

When this mother believed her son’s symptoms were atypical for a child his age, she experienced unwanted uncertainty. Once she was able to make sense of the symptoms and accurately classify them, the uncertainty was less threatening. Parents frequently were relieved to discover that their child’s symptoms were “classic” for vascular anomalies. Similarly, if the specialists provided a concrete diagnosis, parents felt a sense of relief. The father of a 6-year-old girl described the change in his uncertainty after receiving a diagnosis:

[My uncertainty was] high. Just because I thought it was something bad, like life-threatening maybe or, you know, every parent's worst nightmare. [...] Just by the looks on their faces when they first seen it and then when they looked at each other and started saying, "Well it's definitely this or this," and the other's like "Oh, absolutely, it—here's what it is folks," and they explained it and it's like "Wow," [sigh]. [...] It was instant decrease [in uncertainty]. [Participant 8]

For this father, and many other parents, receiving a diagnosis to classify his child's symptoms was instrumental in reducing his unwanted uncertainty. A better understanding of symptom patterns also helped parents create expectations for the future. Even when parents acknowledged the medical uncertainty associated with vascular anomalies, they felt comforted that they knew what to expect in general. For example, the mother of a 10-year-old girl explained, "They talked about the future. That this will have to be watched for probably the rest of her life. So, it's nice knowing that. [...] She knows going in to adulthood what—what's wrong and what to expect" [Participant 28]. Like this mother, many parents' communication with the specialists helped them to accept the long-term uncertainty associated with unpredictable symptom patterns.

Although many parents gained a better understanding of symptom patterns, a few parents continued to feel uncertain after communicating with the team of specialists. For some parents, the unpredictability of vascular anomaly symptoms continued to cause unwanted uncertainty. When asked about her uncertainty after the visit, the mother of a 3-year-old boy explained,

It stays the same. It—I mean, I'm still uncertain. Is it [the vascular anomaly] gonna get better? Is it gonna get bigger? Is it gonna get worse? Is it going to affect him? Is it—ya know, that uncertainty for the rest of his life will be that way for him. So, it's not gonna change. [Participant 14]

Interestingly, earlier in her interview, this mother reported that all of her questions were addressed during her visit. She said, "Yeah! They were all answered," but she continued by explaining,

They answered what they could. They can't see his future. They only know from the past, but because he's different, everybody is different. It may grow for somebody else and it may stay that exact size for the rest of his life. They answered to the best of their abilities, I think. [Participant 14]

This mother acknowledged the inherent uncertainty in treating chronic illnesses.

However, as illustrated by the previous comment, she still had uncertainty about the unpredictability of symptoms associated with vascular anomalies and her inability to develop expectations about her son's future. Parents' inability to determine the full scope of their child's symptoms continued to contribute to feelings of uncertainty.

**Credible Authorities.** Parents' communication with multiple specialists also influenced uncertainty by affecting their perceptions of credible authorities in the care of their child's vascular anomaly. Parents' perceptions of credibility stemmed from their inherent trust in specialists and the specialists' ability to fill the gap left by the previous lack of credible authorities. Initially, most parents conveyed an inherent trust in the specialists because of their specialized training. The father of a 4-month-old boy described this trust in the providers when evaluating decisions:

I guess as a parent you really don't know. You're really trusting of the doctors. To me it's reassuring that this is what they do. It's a specialty. It's not—you're not at a smaller hospital where they're doing a million different things at one time. This is what they do. [Participant 18]

This father acknowledged how the initial credibility he associated with specialists was comforting. Many parents referred to the inherent trust they had in the specialists because of their association with a well-respected children's hospital and because they have a specialization. Whether their trust was inherent or developed during the visit, parents' perceptions of the team of specialists as credible lessened their unwanted uncertainty.

For most parents, the specialists also seemed credible because they were able to provide explanations for their child's condition that their child's pediatrician could not.

The mother of a 10-year-old girl explained how her communication with the specialists was more reliable than any previous communication about her daughter's vascular anomaly:

I feel very, very, very relieved in terms of knowing exactly what is going on in her head and with the veins. That was actually really good news [laughs] and to have it be explained to us because it's never really been explained. That was phenomenal. That—after seeing five other doctors and this is the first time we've gotten a true explanation. So that was great. [Participant 16]

This mother, like many other parents, felt her communication with the specialists helped her identify a more credible source of illness-related information than her child's pediatrician. While many parents expressed respect for their child's pediatrician, they recognized that the specialists were the most credible authority for the care of vascular anomalies. The mother of a 3-year-old boy with a hemangioma acknowledged that she needed to rely on multiple credible authorities to care for her son:

I think I definitely know who to call now and who not to call [laughs]. That may sound mean, but now that we know who has the *correct* information, we will go to those people. [...] I think just because they're specialists in this area makes me feel confident that they probably know more about the vascular system than does our pediatrician. Which, she's a good pediatrician. I'm very confident going to her for *other* things. But, I think when it's a *specific* need, maybe, the specialists are the best way to go. [Participant 12]

Like this mother, most parents reported that the expertise of the team of specialists met a specific health care need that their pediatricians could not fulfill. The specialists' communication alleviated the negative uncertainty associated with the parents' previous perception of the lack of a credible health care provider.

While most parents perceived the specialists to be credible authorities, some parents had doubts about the expertise of the specialists after their visit. The mother of a 4-year-old girl explained how her uncertainty was a result of her doubts about the specialists' competence. She explained,

I just hope to God they know what they are doing. [laughs] Just joking. I just hope to God they know what they're doing. That's all it is. Because, I don't know. I don't—You see, I'm not really satisfied and I am in a way. I feel—kind of confusing feeling so, yeah, I'm not too sure about that. [Participant 27]

While this mother tried to minimize her uncertainty by joking about it, her uncertainty was evident as she began to explore her feelings. Later in her interview, the mother described her uncertainty about the specialists:

My feeling is like, being a parent—I don't know if they really knew how to take care of it or not, you know what I mean. So that was just my opinion. [...] I have been to her family doctor, then we came back and then—I don't know. It's just that I don't know if they deal with a whole bunch of it or not, or what [she] has is very rare. That's kind of what I felt like. I don't know if they deal with a whole bunch of it or not. [Participant 27]

This mother was unsure about the trustworthiness of the care she was receiving and left the visit with anxiety-producing uncertainty. Although she reported receiving sufficient information from the providers earlier in the interview, she had general uncertainty and confusion about the system of health care for her daughter. When parents were not sure the visit was the best thing for their child, they continued to appraise uncertainty as potentially threatening to the child's health.

In summary, Research Question 2 explored how parents' communication with multiple specialists influenced their uncertainty. For a few parents, communication increased uncertainty if it made them feel confused or scared about their child's future. However, when parents' communication resulted in a better understanding of symptom patterns or revealed credible authorities in the care of their child's vascular anomaly, it reduced uncertainty or made it more tolerable.

### **Multidisciplinary Communication and Decision Making**

Research Question 3 asked, "How do parents describe their health-related decision making during their visit to a multidisciplinary clinic?" During their visit,

parents considered decisions such as surgery, medication, compression treatment, and waiting to make a decision until the child was older or the condition resolved on its own. Parents described their health-related decision making by reporting the benefits of multidisciplinary communication and reflecting on their satisfaction with their decisions.

**Benefits of Multidisciplinary Communication in Decision Making.** A primary goal of parents' communication with the specialists was to make decisions for the management of their child's vascular anomaly. As indicated by their high scores on the decision satisfaction subscale ( $M = 6.70$ ,  $SD = .41$ ), parents were generally satisfied with the decisions they made during their visit. Consequently, parents identified many benefits of communicating with multiple specialists to make decisions.

One important benefit of parents' communication was the quantity and quality of information they received to help them make decisions. Most parents felt as though they received sufficient information for decision-making purposes. The mother of a 3-year-old boy described her perceptions of informed decision making:

They just kind of gave us quick pros and cons and explained that for ultrasounds at his age he would have to be put to sleep. Just gave us all of the information so that we wouldn't be rushed with a decision or we wouldn't think that—like lasering, for instance, we don't personally feel the need for him to do that. That's just, this is just how he looks. We don't need to get a big bunch of things done. They didn't seem to try to push us on that at all anything like that, which was nice. [Participant 12]

This mother felt educated about the risks and benefits of treatment and was able to consider her own personal preferences when making a decision. Similarly, many parents appreciated the time the specialists gave them to make a decision. The mother of a 2-year-old boy explained, "Nobody made me feel rushed. Everyone was willing to spend time with us, answer our questions, go over things multiple times" [Participant 15].

Ultimately, most parents felt as though they had enough information and time to make a good decision.

Another important benefit of decision making with multiple specialists is the ability to choose between options. Some parents wanted to cross options off their “list” to narrow possible choices. For example, when the mother of a 15-year-old girl explained what helped her make a decision she said,

Just brainstorming different ideas, “Well, if we do this we could get this answer,” and at least we can cross that off the list and move on to the next thing. Those type of scenarios. Which is good. I want any bad thing crossed off the list [laughs]. [Participant 5]

For this mother, communication that helped her narrow the list of possible treatment options was helpful. Sometimes, parents’ decisions were easier because the communication with multiple specialists helped reveal new treatment options. The mother of a 6-month-old boy explained how one visiting specialist’s introduction of a new treatment option improved her decision making. She stated,

I guess they—they looked at his birthmark and they gave us a treatment that we had—like I said, we had done a lot of research on our own. But you know, when you Google everything under the sun pretty much. So the treatment we decided to go with was something that we hadn’t heard of, so it was helpful to hear that this option was available and that it had worked on like 90% plus of babies and that it had worked in Europe and that they were using it there. So, I guess that was probably the most helpful was to learn something we didn’t kind of already know in our heads that we can’t have surgery and we can’t have this and we can’t have that. So, I guess that was probably the most helpful thing. [Participant 3]

The discovery of new information helped this mother make a decision for her child by expanding her knowledge about the system of care for vascular anomalies. Parents repeatedly described a better understanding of treatment options after the visit. Consequently, with a few exceptions, parents were satisfied with the amount of information they received.

The importance of information for decision-making purposes was also supported by parents' responses to the decision making subscales. The salience of information in parents' accounts of their communication prompted me to further explore the quantitative relationship between information (informed choice) and the other dimensions of decision making (satisfaction, uncertainty, and control). The results of the correlation analysis revealed that responses to the one item measuring informed decision making had significant relationships with all three dimensions (Table 3). Informed decision making demonstrated a significant negative relationship with decision uncertainty ( $r = -.498, p = .005$ ) and significant positive relationships with decision satisfaction ( $r = .409, p = .025$ ) and decision control ( $r = .401, p = .028$ ). These results suggest that parents who were satisfied with the level of information they had after their visit (as reflected by low scores on the item, "I want more information" [before reverse coding]) had less uncertainty about their decision and experienced a greater level of decisional control (i.e., autonomy) after their visit. Ultimately, parents who felt they had made an informed decision were more satisfied with their decision.

**Table 3. Decision Subscale Correlations**

	Decision Satisfaction	Decision Uncertainty	Decision Control
Informed Decision	.409*	-.498**	.401*

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

In addition to sufficient information, another benefit of multidisciplinary communication was collaboration. Not only did parents describe their own contribution to decision making but they also described how the collaborative decision making among the multiple specialists aided in determining the best decision. The mother of a 9-month-old girl with a hemangioma was impressed with the specialists' discussion of treatment



options during the visit and was satisfied with her ability to contribute to the decision making process. She explained,

Usually you're just on the receiving end. You're not in the discussion, which is nice because then you can tell them what you prefer and it will change. They can change their thinking right then rather than you leaving a message and them getting back to you and ya know, in my mind, it's just so much better to be involved—*more* involved in the treatment of your child. [Participant 30]

For this mother, the ability to contribute to the final decision was an important part of decision making. She described how the specialists' acknowledgment of her and her husband's noticeable surprise at the mention of surgery redirected the discussion to other alternatives, such as medication. Most parents agreed that they were able to contribute to the final agreement and in many cases, their personal preferences shaped the final decision.

Collaborative decision making was also beneficial when it revealed agreement among multiple providers. When asked what was most helpful in her decision making process, the mother of a 3-month-old girl responded, "Just, them both agreeing on that, and that's the one me and my husband were already leaning towards, so it kind of like just kind of made it—made us sure that that's the one we wanted to do" [Participant 6]. Communicating with multiple specialists allowed parents to contribute to the process of reaching joint agreement. Mutual agreement during collaboration was especially beneficial in the context of multidisciplinary care, in which parents acknowledged the potential for disagreement. The mother of a 6-month-old boy with a hemangioma described this dynamic among specialists:

[The information] was pretty consistent, because usually the doctors and the surgeons are not like—like the surgeons are like, "Yeah, we'll cut you open and then fix ya up right away," and the doctors are more like, kind of "wait-and-see" types. But this one, I mean the surgeon came in and she's like, "Yeah, you should do the Propranolol [medication]," which is the treatment that we chose. So,

everyone seemed to be on the same page on how—how to kind of course through this stuff, which is nice. Because usually, for adults, I don't think that [agreement] happens as often [laughs] as it does I thought today. [Participant 3]

For this mother, the consistency between different specialties helped her make the decision to pursue medication for the treatment of her son's hemangioma. The father of a 2-month-old girl acknowledged similar benefits of agreement among specialists:

I think everybody's on the same page. Like I said, they're different disciplines. So, you know, if one felt one way and the other felt another, that's good too because they can—they can talk about that and come up the right solution. But in this case, everybody was in agreeance, which means that that's typically the better course of action. [Participant 4]

This father, like most parents, was relieved by the specialists' agreement during decision making but appreciated the advantages of brainstorming and negotiating to come up with the best possible solution. Likewise, the mother of a 15-year-old girl described benefits of multiple providers negotiating to make a decision. She said, "That they can brainstorm together. It's more than one person thinking about a situation and come up with a scenario that another may not" [Participant 5]. Ultimately, parents agreed collaboration during decision making was important in the determination of the best decision. They believed that the synergy of the multidisciplinary health care team resulted in better decisions than they could make with one provider.

**Decision Satisfaction.** Parents' satisfaction was an important element of decision making. Overall, the majority of parents were satisfied with the decision they made, as illustrated by their high scores on the decision satisfaction subscale ( $M = 6.70$ ,  $SD = .41$ ). Whether their decision was to wait or to pursue treatment, with a few exceptions, parents generally agreed it was a "good" decision. For most parents, choosing the least invasive treatment option was an important factor in their satisfaction. When asked how she knew

she made a good decision, the mother of a 3-month-old girl described the benefits of starting with the least invasive option first:

The no side effects [with the topical cream] was the major [factor] and since hers is a lower case—on the lower end of the spectrum, we went for the lower treatment first, and if we need to hit it stronger, we can always come back. You can't start the strong one and reverse back. You can always go up, but you can't go back. [Participant 6]

This mother's satisfaction with her decision was rooted in the fact that she could help her child without worrying about side effects. The inclination to choose less invasive treatments was also indicative of parents' preference for a wait-and-see approach when it was available. The mother of a 2-year-old girl with a vascular malformation summarized the desire for a wait-and-see approach:

Well I mean, I think any time you can do a wait-and-see approach, it's best. As long as there's no risks to it, which they said that there isn't, this isn't going to turn into cancer or anything like that. So in my mind, this is the best, especially since she's two. Okay, doing the MRI, she has to be put to sleep, we can't have her hold—I don't really want to put her to sleep unless there's a really good reason to. So, I really feel like this is the best. As long as they think there's no risk in waiting and seeing then I'm 100% okay with that. [Participant 20]

As this mother described, most parents were relieved when they had the option to choose a wait-and-see approach. If there were no risks associated with waiting, parents were typically satisfied when they could delay or avoid treatment until it was urgent.

Parents also reported that the decision to wait was an “easy” decision compared to having to decide between more invasive treatments. The mother of a 2-year-old girl described this ease:

I came in here sort of expecting that we were gonna have to do that procedure. So when I heard there's absolutely no risk, that most cases that look like this they do a wait-and-see approach. So, when I found that out, I mean, there wasn't really anything for me to think about. If we had had to decide between that, again I can't remember what it's called, and surgery, then we might be having a different discussion. Because then I would've had to make what I would've thought was a tough decision. One of your questions on your questionnaire was, “Did I think I

had to make a tough decision today?” and the answer was “No.” It was a—I thought a really good decision. [Participant 20]

Like this mother, many parents were relieved when they could eliminate fears of surgery by choosing a wait-and-see approach. Similarly, parents reported the decision to wait was easy because it came with the freedom to change their decision at any time. The father of a 2-month-old girl described this flexibility:

We can always change our course of action mid-stream based on what happens and that’s comforting. Right? You don’t have to sit back and say “It’s getting worse, it’s getting worse” and then “Okay, now we’re to our time we can do things.” So I think that’s how it was easy for us to make that decision to wait right now. [Participant 4]

This father’s comments highlighted how the temporal nature of decision making associated with chronic conditions was evident in parents’ evaluations of decision making. For this father, a “good” decision meant that it could change as his child’s needs changed. Similarly, the mother of a 2-year-old girl explained,

We just talked about what they thought was best now and what we would watch out for and if certain things progressed a certain way, what the next course of action would be. So I feel very comfortable that we arrived at the right decision for where we are today and that I understand what would happen going forward if things were to turn bad, I guess you could say. [Participant 20]

Like many parents, this mother remained satisfied with her decision while recognizing the potential for her daughter to require more care in the future. This acceptance of long-term uncertainty was often instrumental in parents’ satisfaction with their decision.

Overall, parents were typically satisfied when the specialist confirmed that a wait-and-see approach was an option. It alleviated stress about treatment and made uncertainty tolerable.

When parents were less tolerant of the long-term uncertainty they were often less satisfied with their decision. Some parents experienced unwanted uncertainty because

they could not predict what may happen during those months (or even years) of waiting.

The mother of a 4-year-old girl explained the risk associated with waiting:

That's [the decision to wait] what I'm not satisfied with. I just want to make sure. Yeah, that's what I'm not too satisfied with. But, like I said, it's only six months. February's not that far. I can handle that and just look at her. She's living a normal life, so she's really hyper and happy, that's all that counts to me.  
[Participant 27]

Although the mother seemed to convince herself that she could handle waiting six months, she later revealed more uncertainty. She explained, "Actually, they answered mostly some of the things. I just want to know when she gets a little bit older. You know, six months is still a long time. You don't know what can happen in six months"

[Participant 27]. This mother's uncertainty stemmed from her fear that the decision to wait may not be the best for her daughter. Her tolerance of the unpredictable symptoms associated with vascular anomalies was low.

The inability to predict the outcomes of their decisions was also source of uncertainty for parents who chose interventions such as medication. The mother of a 9-month-old girl with a hemangioma described her concern about the potential risks of medication:

I am a little worried. Only because there is—nothing is without risk. But, I just—I'm always worried, because you never know how your child is going to react to the medication. She's not allergic to anything, but we don't know. I'm always nervous when you put your kid on something new. It's a medication for your heart, but it's used for something else. You know, what side effects down the road? What might we see when she gets older? I don't know. I'm an over-worrier, so I worry about that stuff. Whereas, surgery for me is less risky than the medicine, even though it seems weird to think that way. [Participant 30]

This mother's concern about unknown side effects of medication was an issue for many parents. Their concern often resulted from apprehension about treating their child's hemangioma with a medication that was approved for alternative uses. Parents explained

that the uncertainty they felt about the potential risks of medication would not be reduced until they saw firsthand that the treatment was working without significant problems.

The results of the quantitative analysis also provided support for the qualitative findings, underscoring the importance of decision satisfaction. Because parents varied in their satisfaction with the final decision, I decided to explore whether decision satisfaction was related to overall satisfaction with the clinic visit. The correlational analysis of the decision revealed that decision satisfaction had a significant positive relationship with overall visit satisfaction ( $r = .477, p = .008$ ). The results suggested that the more satisfied parents were with the final decision, the more satisfied they were with the visit overall. When considered with the qualitative results, this finding revealed that choosing the least invasive option, with the flexibility to change the decision as the child's symptoms progress, may be associated parents' overall satisfaction.

In conclusion, Research Question 3 explored parents' decision making during their visit. Parents' communication with specialists typically occurred with the primary goal of making health-related decisions. With a few exceptions, parents were generally satisfied with their decisions, so their accounts of decision making were characterized by the benefits of multidisciplinary decision making and their satisfaction with their decision. The informed and collaborative nature of decision making was a primary advantage of multidisciplinary care. Ultimately, parents' satisfaction with their decision was the primary aspect of decision making associated with satisfaction with the visit overall.

## **Multidisciplinary Communication and Uncertainty Management**

Research Question 4 asked, “How do parents manage their uncertainty during their visit to a multidisciplinary clinic?” The data revealed that parents managed uncertainty by communicating with the specialists to manage information and seek social support. Parents sought information to reduce uncertainty but also avoided information when they anticipated new information would be overwhelming. Similarly, parents relied on the team of specialists to provide them social support in the form of reassurance and assistance with decision making.

**Information and Uncertainty Management.** It was evident that parents had clear intentions to seek information from the specialists to reduce unwanted uncertainty. Most notably, parents explained that the goal of the visit was to learn more illness-related information about their child’s condition. For example, the mother of a 3-month-old son with a hemangioma described the information she hoped to gain during the visit:

Just to get confirmation that it was, in fact, a vascular malformation that was classic in terms of its growth and its size and discoloration and everything. And to get the next steps. What—when should we be seen next? What should we be looking for? Is there any surgery needed to correct what’s going on? [Participant 31]

Like most parents, this mother wanted to reduce multifaceted uncertainty about her daughter’s diagnosis, symptom patterns, and treatment options. As one mother described, most parents had a strong desire to “just find out where we go from here” [Participant 17]. Ultimately, parents’ primary goal during their visit was to assign meaning to the illness-related events and to find out the options moving forward.

In addition to illness uncertainty, parents also intended to seek information to address concerns about their child’s self-esteem. The mother of a 3-year-old girl with a

vascular malformation explained her desire to alleviate concerns about her child's social future:

[I am uncertain about] how she's going to view it as she gets older. Once she becomes aware of it, is it gonna be a self-esteem issue? Which, you know I think, it's on her face, she's a girl, so I worry about those teenage years and how she addresses that. [...] I came in with—part of my reason for coming was saying, "Is there anything that could or should be done now that would prevent her from having issues later?" You know, to ward off any—like on her wedding day, is she going to hate me because she has something that she didn't want, that I could've done something about? [Participant 9]

This mother, like many parents, expressed concerns about the potential for her daughter's vascular anomaly to affect her self-esteem or social relationships when the condition was visible to others. Likewise, the mother of a 6-month-old boy explained, "'Cause it's in such an obvious place on his face and he gets a lot of attention from it, from adults, and stuff like that. So we wanted to kind of see what our options were" [Participant 3]. The anxiety associated with these potentially negative outcomes provoked parents' intentions to seek information to alleviate these concerns.

***Information Seeking.*** As a result of their intentions to reduce uncertainty, parents communicated with the specialists to seek information. Parents asked questions when they identified illness-related information they were missing or were uncertain about. To obtain this information, parents described a preference for seeking information from credible sources, such as the team of specialists, rather than sources considered to be unreliable. The mother of a 6-month-old boy explained, "I mean, seeing the pediatrician is okay but we really wanted to have it looked at by a specialist, just because we wanted to see what our options were" [Participant 3]. While parents relied on their pediatricians for general information, they preferred to seek information from specialists who were experts in treating vascular anomalies.



Parents frequently made direct attempts to reduce uncertainty resulting from online research. Parents often sought health-related information online before their visit. However, because of the incomplete, inconsistent, and often frightening nature of the information, parents preferred to ask the specialists questions directly pertaining to their child's situation. One mother explained, "I tried to [do research]. There's not a whole lot—my 'Dr. Google Degree' didn't find a whole lot online about intramuscular hemangiomas 'cause they're just not very common. But I did try to" [Participant 22]. Frustrations with the information online strengthened parents' desire to seek information from the providers. The mother of a 3-month-old boy described her frustration:

The first time she [our doctor] mentioned it, I came right home and of course Googled it and started looking it up on the Internet, which is a horrible thing to do. [...] There's just so many scary things on the Internet and you don't know—I guess WebMD is a good source of information, but who really knows if the stuff published is good information or not. There's a lot of scary scenarios out there and worst-case scenarios, so I kind of stopped doing that until we got in contact to the doctor and who could really answer questions relative to my son's case versus just blindly Googling things and looking at pictures. [Participant 31]

For this mother, the benefit of seeking information during the visit was to get information specific to her son's case. This was a challenge for many parents due to the rarity of vascular anomalies. Many parents expressed similar frustration with how little information they could locate about their child's condition. The information they did find was often incomplete or was not relevant to their child's condition. The lack of understanding about their child's full diagnostic picture prompted information seeking behaviors to obtain new information.

Parents also sought information to confirm or reject existing beliefs about their child's vascular anomaly. The mother of a 2-year-old girl described her direct information seeking behaviors after her daughter received a different diagnosis during the

visit than the diagnosis she received from a previous provider. She recalled, “I quizzed them. There you go, that’s the best way to say it. I quizzed them on it because of the fact that it was something else than what I was told it was” [Participant 25]. This mother continued to explain how the specialists took time to explain her daughter’s condition and even drew pictures to give her a better understanding of the diagnosis. She reported that her uncertainty decreased after her visit. Similar to this mother’s experience, parents’ communication with the team of specialists allowed them to reduce uncertainty stemming from conflicting information about their child’s diagnosis and treatment options.

Parents also used direct requests to seek information that addressed the fear that their child’s condition was life threatening. The father of a 6-year-old girl described his direct request for information about the severity of his daughter’s condition. He explained, “When I said, ‘It’s nothing life threatening?’ and he said ‘No’ and I just [sigh] I took a big deep breath and I said, ‘So, it’s nothing bad?’ and he said, ‘No,’ he said, ‘We’re sure it’s nothing bad’” [Participant 8]. Like this father, many parents expressed significant reductions in unwanted uncertainty after they inquired directly about the severity of their child’s condition and the urgency of treatment. Parents frequently reported uncertainty would have been more stressful if their child’s condition had been worse. The mother of a teenage boy explained, “If—if the pain would’ve been there, worse, I would’ve probably felt different. But, being that it got better, is the uncertainty there? No” [Participant 1]. Her feelings were similar to many parents who acknowledged uncertainty was tolerable because their child’s pain or symptoms could always be worse.

As illustrated above, parents’ communication was focused on seeking information to reduce uncertainty. The success of parents’ information seeking was evident from

frequent reports that all of their questions were answered during communication with the team of specialists. The mother of a 6-month-old boy described her satisfaction:

They explained everything very thoroughly, and at the end it was like, “Yeah, do you have any questions?” and I’m like, “No, I actually think you visited all of my questions in the course of your talking.” So that was kind of—it’s kind of nice not to be left with, “Oh my gosh, I don’t know what to do,” and everything.  
[Participant 3]

This mother reported that she and her husband asked questions during the visit because they have a low tolerance for uncertainty. Information seeking helped parents leave the visit with a better understanding of their son’s condition and reduced uncertainty.

Parents’ information seeking was often successful because they were able to communicate with multiple providers and receive multiple opinions. The mother of a 6-month-old boy explained the benefits:

I think just having a lot of different opinions is probably good. Just because, you know, one person may have had an experience with something that another doctor hadn’t or they may just within talking to one another they may kind of spark up a new idea of something and I just think a lot of great minds in one place can’t be a bad thing. [Participant 12]

Like most parents, this mother acknowledged that relying on multiple specialists for information resulted in obtaining adequate and more accurate information. The father of a 2-month-old girl explained, “I don’t believe that everybody is fantastic in everything. They’re fantastic in—that’s their specialty. Right? One thing. So, I think it’s good to rely on others and their specialty to work as a team” [Participant 4]. This notion that specialists are authorities in one particular area highlighted the benefit of seeking the opinions of multiple specialists to effectively manage information. For example, the mother of a 12-year-old boy described her information seeking:

I liked it a lot to be able to ask the specific questions to their area of expertise. It is, to me, very helpful to have a team there versus just one doctor that has consulted with the other ones and said, “Well, I think this is what they meant,” or

“This is what they said, but I’ll have to double check.” So it was nice to be able to directly ask each one the questions that we had. [Participant 22]

This mother described how the information from different specialists was beneficial and, although she admitted she still had uncertainty, she reported that several of the worries she had before the visit decreased. The examples above highlighted parents’ information management as a successful strategy for managing uncertainty about their child’s condition. Parents’ communication typically helped them seek information from multiple providers to reduce uncertainty.

Although parents’ information seeking was often successful in reducing uncertainty, it also resulted in their accepting of uncertainty associated with caring for vascular anomalies. The father of a 2-month-old girl explained,

But still, still—it is scary because, you know, you ask, “Is it going to get really, really bad?” Well, there’s no way of knowing. I mean, they’re [the doctors] uncertain too, right? They never know what’s going to happen. They can only give us the facts of history and studies and—and experience. But that outweighed the worry, the results of that. [...] They weren’t uncertain about maybe how the treatment would go, but they can’t—everybody is different. Everybody’s chemical makeup is different. That’s exactly pretty much how they put it. Everybody is different; every hemangioma is different on the same body. So, you don’t know what it’s going to do until you get into it. It could be great results or it may not be so great results, but they were very reassuring that as we move forward, and in a few years, it gets better. It’s the natural course for speeding up that natural course, we hope. So that’s comforting. [Participant 4]

The father expressed how his attempts to seek information about his daughter’s hemangioma revealed that even specialists have uncertainty when it comes to vascular anomalies. Although he initially considered the uncertainty frightening, like many parents, this father’s communication with the specialists helped him accept that uncertainty cannot be completely eliminated because of the inherent uncertainty associated with vascular anomalies. The fact that the specialists shared their uncertainty provided reassurance and helped to make the uncertainty less upsetting.

While the abundance of information available during first-time visits can be helpful, it also can act as a barrier to effective uncertainty management. Parents frequently addressed challenges associated with seeking information to reduce uncertainty. The mother of a 2-year-old boy with Klippel-Trénaunay syndrome explained how the information-richness of the environment was overwhelming:

Overwhelming, a little bit. It's a lot of information to take in in such a—it's a lot of information to take in. I told you, I think, when you came in that I was writing notes and I was writing notes so I don't forget things. I think you see all this or you hear everything they're telling you and you're trying to process it, and I think when I leave here I'm going to keep processing it, and I know I'm going to have questions that I didn't have in the room while they were there. Which is—it's happened to us before, so I kind of expect that to happen. [Participant 15]

As this comment illustrated, the sheer volume of information presented to parents during the visit was often overwhelming and sometimes anxiety-producing. In fact, some parents acknowledged receiving information from multiple providers was unnecessary. When parents saw the specialists one at a time, they sometimes considered the second (and any additional) specialist to be superfluous. One mother elaborated on this notion:

The team of doctors—I understand that maybe some people feel that they benefit from that. But, when it's the same repetitive information from each doctor, I didn't feel the need to have that. 'Cause the first doctor, she basically took care, and then the second doctor came in and just reinforced it. That was—that was it. Maybe, like if the first doctor went in and insists that you decided it wasn't that much of an urgency and they could like pass on to the next doctor, "You don't need to see this person." [...] 'Cause I didn't have the questions that I did for the first one as I did for the second one 'cause I already knew what the first one said was basically what the second one was already repeating. [Participant 1]

This mother described how her information seeking behaviors changed as the visit progressed. She did not directly seek information from the second provider because the information she expected to receive was not of value. Consequently, her information seeking behaviors changed over the course of the visit.

Parents who did not favor seeing multiple providers often commented on differences in information-seeking behaviors between spouses. For example, the father of a 7-month-old girl commented on these dynamics:

My wife would much rather see more people than less people. But, I guess I'm the opposite? [...] For me, I don't know, I like one answer. But, she wants to ask all the questions. She's got all the questions. You know, usually the first doctor that came in, he gave us the answer and I'd have been perfectly fine. He gave us a treatment plan and I'd be out the door if I was a single dad. But, she likes the fact that two more doctors came in. [Participant 19]

This father, like many parents, revealed the potential for different information seeking behaviors between spouses. His comment revealed that if he had been at the visit by himself he would have managed information differently. The dynamics of information seeking between spouses confirmed that parents' information seeking did not occur in isolation and was influenced by the communication of multiple parties involved.

In some cases, the differences in information preferences between spouses helped parents manage information collaboratively. For example, the mother of a 12-year-old boy explained,

My husband definitely asked more questions than I did. That's just his nature to ask more, and I tend to listen. I did ask a few questions, but, I tend to listen more and he tends to ask more questions. [Participant 22]

For this couple, their different preferences for active versus passive information seeking were evident. Their information seeking behaviors did not conflict, so they were able to seek information jointly. However, it was possible for parents' information seeking strategies to negatively affect their spouse's ability to manage uncertainty. For instance, the father of a 7-month-old girl said,

For me, [talking to multiple doctors was] a little overwhelming but I think for my wife that's good. [...] It was just too much—too much for me. I prefer one person coming in, giving us the diagnosis, and then moving on. [Participant 19]

This father felt overwhelmed by the dynamics of communicating with multiple specialists but acknowledged that it was important for his wife to seek information from multiple sources to manage her uncertainty. Evidently, the information-rich context was often helpful for parents' information seeking, but also presented some unique challenges.

***Information Avoiding.*** In addition to seeking information, parents described circumstances during their visit when they avoided information to manage uncertainty. As demonstrated above, it was common for parents to feel overwhelmed by the sheer amount of information they were receiving from the specialists. For example, one mother described how the presence of multiple specialists increased the potential for conversations about other health risks. She explained, "We need to deal with one issue at a time and it is kind of overwhelming sometimes to be surrounded by all these doctors and they are like 'Yeah, did you notice this? and...'" [Participant 3] For this mother, when a specialist brought up her son's slightly flat head she felt overwhelmed by the information that was not relevant to her son's vascular anomaly and opted to avoid further discussion on the topic.

Parents also avoided information about treatment options that were not imminent. The mother of a 2-year-old girl with a vascular malformation explained her choice to avoid information about treatment options:

I don't think I need to [know about each option] at this time either. I don't necessarily—I didn't necessarily want to explore that because I don't want to worry myself. They really feel that the wait-and-see approach is what is needed and I trust their opinion. So, if we do need to end up going down a different road they said that they would order the MRI first so that would give us a better scan of the area and it would let us know better what we're dealing with so then we can discuss whether we do that—whatever—that other option or we do surgery or whatever. So at that point, I would probably have more questions. But, I didn't care to explore those now. [Participant 20]

For this mother, the inability to act on information about future treatment options meant that she preferred to avoid the information temporarily. For most parents, delaying potentially overwhelming information allowed them to focus on short-term goals and manage more immediate forms of uncertainty.

Other parents wanted to avoid information that increased uncertainty by giving them more options. The mother of a 9-month-old girl with a hemangioma described her tendency to avoid information that could complicate potential outcomes. She said,

I feel like I got enough information. I don't like to be overwhelmed with information. I don't [pause] I don't want a study that says one thing and then another study that says the exact opposite. I'm just like, "Don't do that to me."  
[Participant 30]

While this mother answered "no" when asked if she wanted to avoid information during her visit, it was clear that she did not welcome all information. This contradiction was common for the parents who denied wanting to avoid information during the interview but also admitted wanting to delay difficult conversations for the future. Like many parents, the mother above recognized the benefit of maintaining her current level of uncertainty. For example, she explained, "I thought that everything that we got was helpful and I don't know what I don't know [laughs]" [Participant 30]. Similarly, many parents acknowledged their uncertainty and were aware of how much information was helpful versus detrimental in managing the uncertainty.

**Social Support and Uncertainty Management.** In addition to managing uncertainty by seeking and avoiding information, parents addressed uncertainty through social support. Overall, parents reported high levels of perceived support during their interviews. Many parents reported feelings of comfort from knowing their child was receiving good care. For example, the mother of a 2-year-old boy explained:



I feel like it's very comforting to know that there are so many people that are willing to come help you care for your child and so many people that are—that are going to help you when you've got all these avenues and different outlets on how to treat different things. So, that was kind of nice. [Participant 15]

Like this mother, most parents were comforted by their perceptions of the specialists as sources of support. Knowing they had access to information but also to individuals who were willing to help them was reassuring. Parents also identified the providers' emotionally supportive communication and good rapport with their child as beneficial in managing uncertainty. The mother of a 3-month-old girl described,

They were very friendly whenever they came in. Very easy to talk to and very personable. As far as talking to you and interacting with the baby and talking to her. And making sure she was comfortable helped a lot.” [Participant 29]

These affective communication behaviors were important to parents' perceptions of the team of specialists as a support system. Parents consistently described the specialists as friendly and helpful. In fact, many parents were comforted that the specialists encouraged them to call at any time if they have questions, creating the perception that their ongoing uncertainty could be managed.

While perceived emotional support was helpful, the decision-making support parents received from the providers was most influential in reducing uncertainty. Parents frequently reported decision-related uncertainty from the dilemma of wanting to help their child but not wanting to administer unnecessary treatments. For example, the father of a 4-month-old boy explained, “As a parent too, I mean to me I don't want him to be uncomfortable [because of his vascular anomaly], but again too, I don't want them to operate on him if they don't have to” [Participant 18]. Consequently, parents reported a strong desire to seek support from the specialists to guide their decision making. The mother of a 2-year-old boy with Klippel-Trénaunay Syndrome explained,

They're telling us risks and benefits and kind of looking at us to say—waiting for us to make a decision, and I just said “I need you to make this decision for me or just tell me what we should do.” [Participant 15]

While parents respected their decision-making autonomy, they also described autonomy as a barrier to managing uncertainty effectively. The father of a 2-month-old girl with a hemangioma explained the challenges of autonomy:

I will say that they're all really, really good with giving options and talking through it, the pros and cons, to help you make your best decision. They certainly do not want to make it for you or pressure you into anything, that was very apparent and it was said that they were serious about that. But also, maybe to a fault, we look to doctors to not tell us what to do, but to guide us in the right direction that's best for, because we're—I mean, we're idiots when it comes to this, right? We come to them because that's their specialty. So, there was a time when you're kind of wanting more, “Should we just wait? In your best decision, what do you recommend?” [Participant 4]

This father's experience captured most parents' desire for validation and support in their decision making, which they achieved by communicating with the specialists. This father indirectly requested the specialists' support by seeking validation that he was making the right decision. He described his process, “In a roundabout way, I stopped and said, without saying, ‘What should we do?’ right, ‘Would you agree with me that there is nothing wrong with waiting a couple weeks to do this rather than go ahead and moving forward?’” [Participant 4]. By asking if the specialists agreed, he was inherently requesting guidance in the decision making process. Their reassurance gave him the validation that he was making a good decision.

Other parents described more direct attempts at requesting the specialists' support. The mother of a 2-month-old girl with a hemangioma explained her inquiry:

You ask them. Them being mothers and wives and all that and looking at the little baby, I just kind of asked them “What would you do if this was your child?” And that is kind of what I would've—if they told me “Go ahead and get laser treatment; that's what I would do for my child,” that's probably what I would've

chosen. So basically, getting their advice from a medical standpoint was how I made my decision. [Participant 10]

Like many parents, this mother relied on the providers as a social support system to help her make a decision. Their reassurance helped parents cope with the uncertainty and stress associated with health-related decision making. These requests for advice also illustrated the trust the parents had in the specialists as trusted support providers.

In conclusion, Research Question 4 asked how parents managed uncertainty during their visit. Parents' communication with the team of specialists helped them manage uncertainty through the management of information and the receipt of social support. Initially, parents had a strong desire to seek information to reduce uncertainty. However, the information-rich environment of multidisciplinary care made them quickly realize the likelihood of receiving potentially overwhelming or distressing information. Parents adapted to the environment by avoiding information to keep uncertainty at a tolerable level. In addition to information management, parents also managed their uncertainty by seeking social support. Ultimately, most parents felt comforted by the specialists' emotional support, but the unwanted uncertainty they faced making health-related decisions for their child prompted them to seek additional support. The decision-making support parents received from the specialists was significant in their uncertainty management.

## Chapter Five: Discussion and Conclusion

The results of this study provide a better understanding of parents' uncertainty management and decision making experiences during their first visit to a multidisciplinary vascular anomaly clinic. Previous research has focused on uncertainty and decision making immediately following a cancer diagnosis and during end-of-life care. Thus, my goal for the current study was to expand the existing literature by examining how parents' communication influenced uncertainty management and decision making for their child's chronic illness that required coordination of multiple specialists. A primary strength of the study is the time point at which I collected data. Parents were visiting the clinic for the first time, so I was able to explore how communication with multiple specialists played a role in parents' uncertainty management and decision making in light of communication with previous providers who referred them for specialized care. This context is theoretically important because current uncertainty management theories and decision making models address patients' experiences but do not address the experiences of *parents* of patients. Additionally, the multidisciplinary context is rich in information exchange, which enables me to build on existing literature by examining how parents communicate to make decisions and manage uncertainty in medically complex situations.

The findings also have many significant implications. First, the study provides important insight into how communication influences parents' reappraisals of uncertainty. This finding is a significant contribution to the research on uncertainty management because it reveals how communication with specialists can help parents become more tolerant of uncertainty and learn to manage uncertainty more effectively by

reappraising uncertainty differently. Next, the results reveal the complex dilemmas parents face while managing uncertainty. An awareness of these dilemmas helps parents and specialists acknowledge the multiple (and potentially competing) uncertainty management goals that parents must address when communicating with specialists. Lastly, the study has important implications for improving medical decision making during parents' first visit to a multidisciplinary clinic. While shared decision making and mutual agreement are important in decision making, the study reveals that autonomy may at times deter from effective decision making because parents often wish to rely on the advice and reassurance of health care providers to make decisions. I discuss these theoretical and practical implications below. I conclude with an overview of the future directions and limitations raised by my findings.

### **Reappraisal of Uncertainty**

Parents' reappraisal of uncertainty emerged as a common thread that connected the results of the research questions. The findings suggest that communication with multiple specialists does not necessarily eliminate parents' uncertainty but instead leads to a reappraisal of uncertainty. In the current study, parents typically arrived at their first visit with intentions to seek information to reduce unwanted uncertainty. Communicating with a team of specialists can help parents become more tolerant of the long-term uncertainty associated with vascular anomalies, and as parents become more accepting of uncertainty, they become more comfortable engaging in communication strategies (e.g., avoiding information) to maintain a tolerable level of uncertainty.

For parents of children with rare conditions like vascular anomalies, communication with pediatricians can lead to a negative appraisal of uncertainty.

Traditionally, a child's pediatrician is a trusted source of information for most illness-related information. However, parents frequently discover their child's pediatrician is not a dependable resource for diagnosing and treating complex chronic conditions. When parents receive incomplete, inconsistent, or incorrect information from their trusted pediatrician, it can cause heightened uncertainty. For example, parents may fear the worst for their child's future if their pediatrician gives them an incomplete diagnostic picture, convinces them that surgery is the only treatment option, or leads them to believe that significant health risks are possible. The present findings confirm that the lack of a credible authority and a basic understanding of illness symptoms in primary care contribute to parents' negative appraisal of uncertainty because it is potentially threatening to their child's health.

If parents appraise uncertainty as a danger before their visit to a multidisciplinary clinic, communication with specialists can help them reappraise uncertainty as tolerable in two primary ways. First, parents' communication can reveal that chronic uncertainty is a normal part of caring for children with vascular anomalies. For example, the specialists can help parents accept that vascular anomalies manifest differently in different children, so they must learn to monitor the symptoms as the child continues to grow. The present findings revealed that parents acknowledged specialists are often unable to answer every illness-related question, because the specialists are also uncertain about the evolution of some vascular anomalies and the outcomes of certain treatments. While the inability to answer illness-related questions was often the root of unwanted uncertainty during parents' communication with pediatricians, it was not as threatening during communication with the specialists because of the specialists' perceived credibility. As

experts, the specialists' disclosure of uncertainty helped parents reappraise medical uncertainty as less frightening because it confirmed that uncertainty is expected when caring for vascular anomalies. For example, when pediatricians suggested waiting to pursue treatment, parents tended to assume the pediatrician was being dismissive of their child's condition and appraised the uncertainty as a potential danger. Conversely, when the team of specialists confirmed the wait-and-see approach was a good decision, parents accepted the decision to wait as useful in managing their uncertainty. Similarly, parents' perceptions of the specialists as sources of social support helped them feel less threatened by uncertainty and feel more confident in managing uncertainty collaboratively with the specialists going forward.

Secondly, parents' communication with specialists can lead to a reappraisal of uncertainty by helping them accept the temporal nature of uncertainty. In the current investigation, parents' unwanted uncertainty was often increased by the anticipation of having to make a treatment-related decision. The stress of choosing between surgery or other procedures that require anesthesia can cause parents to dwell on concerns about putting their young child to sleep and subjecting their child to painful treatments. During their current visit, parents looked at decision making differently when communication with the specialists revealed that waiting to pursue treatment was an acceptable option. Suddenly, decision making was less of a burden because the parents were no longer choosing between seemingly undesirable options. If parents did decide to pursue treatment, such as medication, they acknowledged the long-term uncertainty associated with the outcomes of treatment, but were often reassured that they could monitor their child's progress over the course of several follow-up visits. These checkups help parents

maintain a sense of stability in the context of ongoing uncertainty. Consequently, parents' uncertainty may not be eliminated during communication with specialists; their uncertainty can become less threatening when the dangers they associate with treatment and the stress associated with making a difficult decision are not as relevant or imminent as they once were. After their current visit, parents' reported perceptions of short-term stability coupled with their acceptance of long-term uncertainty suggested that communication with specialists helped them reappraise long-term uncertainty as tolerable.

The present findings also suggest that as parents become more accepting of uncertainty, they become more comfortable engaging in communication strategies to maintain (rather than reduce) uncertainty. Avoiding information about treatment options that are not urgent is an important strategy for maintaining uncertainty for parents of children with vascular anomalies. As previously mentioned, parents' communication with specialists often confirms that a wait-and-see approach is the best decision for young children. While periods of waiting are often associated with increased uncertainty (Clarke-Steffen, 1993), in the context of caring for children with vascular anomalies, there are several benefits to a wait-and-see approach when there is no immediate threat to the child's health. These benefits include the freedom to decide a more appropriate treatment as the child's symptoms continue to develop and the ability to wait until the child is old enough to decide if they want to pursue more invasive treatment options. When parents in the study acknowledged the benefits of delaying decision making, it made the uncertainty associated with waiting less threatening. Consequently, parents chose to temporarily avoid conversations about future treatment decisions out of fear that



discussing options such as surgery may create unnecessary worry. Despite their initial desire to seek information about their child's vascular anomaly, parents' reappraisal of uncertainty creates a new desire to maintain a tolerable level of uncertainty, which helps them effectively manage uncertainty to establish coherence.

### **Dilemmas in Uncertainty Management**

Another overall theme of the current results is the dilemmas of managing uncertainty in multidisciplinary care. These dilemmas arise primarily from the information-rich context of multidisciplinary care. Parents' attempts to reduce uncertainty by seeking information were often complicated if they dreaded certain types of information, felt overwhelmed by the amount of information received, or dealt with conflicting information preferences with their spouse.

One dilemma parents face when seeking care at a multidisciplinary clinic is managing simultaneous desires for as much information as possible and desires to avoid certain types of information that may be upsetting. Because their previous attempts to seek information were unsuccessful, parents in the current study typically arrived at their current visit with a strong desire to seek information about their child's illness. Parents want information about their child's symptoms, a definite diagnosis, the options for treatment, and the influence the illness will have on their child's future. Even when parents insist they want information, they are still concerned that coming to a specialist may reveal negative certainty about their child's condition. For instance, in the present study, parents wanted information about their child's condition, but they did not want the specialists to confirm the condition was cancer or something life-threatening. Additionally, parents were frequently concerned that the specialists would say that

surgery was the only option for treatment. Parents must manage competing uncertainty goals during communication with the team of specialists, and as a result, they may avoid asking questions about side effects or other health risks. One parent may also rely on his or her spouse to ask questions and process information because the spouse is more prepared to handle the potential negative certainty associated with seeking information.

Another uncertainty management challenge is that parents' initial desire to seek information is often met with feelings of being overwhelmed by the amount of information they receive. Communication with multiple specialists is inherently more complex than the traditional parent-provider communication that occurs with pediatricians. During their interviews, parents consistently commented on their feelings of being overwhelmed by the number of providers they saw and amount of information they received. When parents were overwhelmed by the information-richness of the visit, their original goals of asking questions and making decisions often shifted to efforts to try to process the information they received. This can derail their uncertainty management efforts and make decision making more difficult, especially when parents lack the specialized knowledge or cognitive resources needed to process complex information. While most parents in the study considered seeking information to be the most helpful approach to managing uncertainty, they also realized that seeking information from multiple specialists may lead to an overwhelming amount of information that increases unwanted uncertainty.

When a child's parents have different, and often conflicting, information management preferences, it can also make uncertainty management more challenging. Parents in the current sample commented on how their information preferences differed

from their spouse. In some cases, their differences were helpful in collaboratively managing uncertainty. For example, when parents rely on their spouse to ask questions, it can help them manage their own uncertainty by assisting them with gathering the information they need. However, in many cases the difference in information preferences makes uncertainty management more difficult. When one parent encourages as much information as possible and the other parent prefers to seek limited information (e.g., just enough to facilitate decision making) or to avoid specific information (e.g., risks and side effects), it can result in one parent feeling overwhelmed and the other feeling constrained. The results of my study suggest that when multiple parties are involved, uncertainty management can be challenging because parents' control over the exchange of information decreases. Parents must focus on managing their own uncertainty while their spouse or partner is also managing uncertainty. Ultimately, if a child's parents have conflicting goals, it can make uncertainty management more challenging.

### **Theoretical Implications**

The results of this study have multiple theoretical implications. First, the findings support the tenets of Mishel's theory of uncertainty in illness, especially the role antecedents play in the appraisal of uncertainty (Mishel, 1988; Mishel & Braden, 1988). Specifically, my analysis reveals the importance of symptom patterns and credible authorities in parents' appraisal of illness uncertainty. This is an important extension of Mishel's theory, because it confirms that uncertainty experiences are similar for *parents* of patients and the patients themselves. When the symptoms of a child's illness are not predictable or attributable to a clear cause, parents' uncertainty is increased. A basic knowledge of the "usual" symptoms gives parents the confidence to monitor their child's

symptoms (Mishel & Braden, 1988). But in the case of vascular anomalies, parents had trouble making sense of their child's symptoms, so they experienced uncertainty because they feared the symptoms were threatening.

The results of the current study also underscore the importance of a credible authority in the appraisal of uncertainty. The absence of a credible authority is often associated with a danger appraisal of uncertainty (Mishel, 1988). For instance, parents may assume the worst if their pediatrician appears to be incapable of interpreting symptoms and providing treatment. Credible authorities influence uncertainty by giving parents advice about the management of their child's illness, and providing a "logical structure" to illness-related events (Mishel, 1988, p. 228). When pediatricians are unable to fulfill either of these needs, their provision of a referral to a multidisciplinary disease-specific clinic is important. Ultimately, the results shed light on the potential for changes in credible authorities (and thus changes in uncertainty) over the trajectory of a chronic illness. When pediatricians are unable to provide adequate care, specialists may replace pediatricians as credible authorities in the context of complex chronic illnesses, which, in turn, affects uncertainty.

The results of the study also support the principles outlined in the theory of uncertainty management (Brashers et al., 2000). The findings underscore the importance of communication as a tool for managing uncertainty through information management and social support (Brashers, 2001; Brashers et al., 2004). My analysis confirmed that parents' uncertainty is not inherently negative. The results suggest that parents appraise (and reappraise) uncertainty through communication with others. This is an important contribution to uncertainty management theory (Brashers et al., 2000), because the

original theory suggests that cognitive appraisals of uncertainty lead to certain communication behaviors but does not explore how communication shapes appraisals of uncertainty. Historically, appraisals of uncertainty have been associated with emotional responses to uncertainty, such as fear or hope (Mishel, 1988). Even in the context of chronic illness, the theory suggests that the range of emotional responses associated with the ebb and flow of chronic uncertainty shape appraisals of uncertainty (Brashers et al., 2000). The results of the current study suggest that uncertainty appraisals are shaped by interactions with others. For example, parents of children with vascular anomalies tend to develop negative appraisals when communication with pediatricians or attempts to seek information online create feelings of fear or frustration. Similarly, parents' communication with specialists in search of information and social support may reduce feelings of fear or frustration and help them reframe their appraisals of uncertainty as more tolerable. In both cases, parents' appraisal of uncertainty does not exist in isolation—it is a product of communication with others. The mutually influential link between communication and uncertainty appraisals is an important contribution to the theory of uncertainty management.

### **Practical Implications**

The findings of the current study also have practical implications for improving decision making in the context of multidisciplinary care. First, the results are consistent with previous literature demonstrating that shared decision making is an important benefit of multidisciplinary care (Katz, 1984; Makary, 2011). When mutual agreement exists between parents and specialists, it improves patient-centered decision making by helping parents make a decision that is consistent with their own preferences for what is

best for their child. However, the results of the study confirm that it is beneficial for specialists to include parents in the collaborative decision making process. Parents of children with unknown chronic illnesses (who have been referred to a team of specialists because of the rarity of their child's condition) benefit from understanding how specialists arrive at a final diagnosis (not just receiving the final diagnosis) and from contributing to the decision making process. When the specialists disclose their own medical uncertainty, it encourages shared decision making by inviting parents into the conversation (Henry, 2006; Politi et al., 2007) and makes the specialists seem "more human" to parents who may be intimidated by the power of health care providers. This finding suggests that specialists who are hesitant to disclose medical uncertainty can benefit from framing the disclosure as a useful tool for decision making.

The findings also have important implications for the role pediatric specialists play in parents' decision making. While parents' autonomy is important for patient-centered decisions, the results suggest that parental autonomy also may act as a barrier to effective decision making in complex and uncertain situations. When health care providers insist on giving parents full autonomy in decision making, they are often assuming that parents' preferences are static and well-established (Epstein & Street, 2011). However, in situations that are complex and unfamiliar, individual preferences are typically unstable and are influenced by how a situation is framed. Consequently, when made independently, parents' health-related decisions are often "neither truly informed nor autonomous" (Epstein & Street, 2011, p. 456). The results of the current study confirm that, in situations that are characterized by complex information, parents rely on pediatric specialists to help them make decisions. In the context of caring for vascular

anomalies, the specialists' assistance is not considered a threat to parents' autonomy; it is considered a form of social support that helps parents manage the stress associated with making a good decision for their child. Ultimately, when parents ask health care providers, "What would you do if this were your child?" they are not only requesting information about their child's prognosis, but also are confirming their trust in the provider as a decision making partner. However, many parents request this information indirectly. Therefore, health care providers must learn to recognize requests for advice and support and should be prepared to offer their honest recommendations as if they were caring for their own child. The trust they can build by providing social support may be instrumental in parents' decision making during a time of heightened uncertainty.

Another practical implication of the study is the finding that parents of children with chronic illnesses often prefer a wait-and-see approach when managing their child's illness. Previous literature suggests that during end-of-life care, parents are typically seeking confirmation that they have exhausted all treatment options before they refuse additional interventions (Hinds et al., 1997). Conversely, the results of the current study suggest that parents of children with chronic conditions that are not life-threatening seek confirmation that a wait-and-see approach is preferred above all possible treatment options. For example, parents of children with vascular anomalies experience relief knowing they can continue to monitor their child's symptoms and withhold treatment until their child is older or treatment is imperative. While parents may feel guilty during end-of-life care if they prematurely withhold treatment (Sharman et al., 2005), parents of children with lifelong chronic illnesses may feel guilty if they administer unnecessary treatments (Cohen, 1993a). This suggests that specialists would do well to explicitly

validate parents in their decision to wait to take further action in their child's treatment in the case of vascular anomalies. By doing this, the specialists can help parents realize that choosing to wait, which parents sometimes consider to be a "non-decision," is actually a valid decision in the care of vascular anomalies. This reassurance can help parents accept that they are still a "good parent" to their child if they choose to delay or withhold treatment for their child's vascular anomaly.

### **Limitations**

The results of my analysis help expand our understanding of parents' uncertainty management and decision making in the context of multidisciplinary care. However, the contributions are not without limitations. First, the small sample is a threat to the transferability of the findings. The small sample size did, however, allow me to develop a more in-depth understanding of parents' experiences than I could have with a larger sample. The use of multiple coders and member checking also confirmed the accuracy of the findings as in-depth representatives of parents' lived experiences. Next, the low reliability of the decision-making subscales presents limitations in the interpretation of the quantitative results. Interpreting analyses with subscales with low reliabilities and one-item measures must be done with caution. Consequently, I only conducted the quantitative analyses in support of the qualitative results and not as independent claims about the nature of parents' decision making. The low reliability of the scales also reveals the need for future research focused on developing validated scales tailored to the decision-making experiences of caregivers rather than patients. Validated scales for caregiver decision making would also be beneficial for future research exploring whether



uncertainty management and the appraisal of uncertainty are related to decision outcomes.

Next, the composition of the sample presents several limitations. I collected data from only one of the child's parents, which prevented me from exploring the collaborative nature of uncertainty management when two parents were present at the visit. While parents frequently commented on the communication dynamic between themselves and their spouse, future research should seek to capture the dynamic interplay between spouses during uncertainty management and decision making. Similarly, future research would benefit from exploring the child's (i.e., the patient) role in decision making and uncertainty management in the context of vascular anomalies. At a young age, children are able to ask questions and express preferences, so considering the role the child plays in the communication interaction would be valuable. Another limitation of the sample was the wide range in time that had passed from the child's initial diagnosis to the current visit. While some parents visited the clinic almost immediately after their child received a diagnosis, other parents waited several years to seek care. This also resulted in a sample that represented children of different ages. It is possible that parents' uncertainty management and decision making experiences are affected by the time between a diagnosis and a referral to a specialist. However, the similarities identified in the findings suggest that many of the same benefits and challenges of communication with multiple specialists exist regardless of how much time has passed since the initial diagnosis. Nevertheless, parents' tolerance of uncertainty and decisions may be affected by their child's age, so future research would benefit from examining differences in

uncertainty management for parents of newborn or infant children versus parents of adolescent children or even adult children.

Another limitation is my decision to gather data at a disease-specific clinic, which resulted in a homogenous sample affected by the same chronic illness. Uncertainty management and decision making experiences may be dependent on type of chronic illness. This opens the door for future research to explore multiple chronic illness contexts to verify the current findings. It is likely that parents of children with any health condition requiring multidisciplinary care experience similar uncertainty management and decision-making experiences because of the referral from their regular pediatrician to a team of specialists. Similarly, it is likely that uncertainty management and decision making are influenced by larger constructs, such as family communication patterns, personal tolerance of uncertainty, and previous health-related experiences. Accounting for these variables was beyond the scope of the current study, but they are important considerations for future research exploring uncertainty management. Likewise, my decision to collect cross-sectional data means that my findings are constrained by their temporal nature. In the context of chronic illness, cross-sectional data only provide a snapshot of the full trajectory of experiences. The findings of the present study provide great insight into parents' *first* visit to a multidisciplinary clinic, but future research is needed to explore the full scope of parents' long-term uncertainty management and decision making. The results are also specific to chronic illnesses that are manageable and may not apply to severe or terminal illnesses. Additionally, my interviews were short in length. While short interviews were effective for answering my current research questions, future research would benefit from more comprehensive interview protocols.

My bias as a researcher is another potential limitation that must be considered. My experiences as an individual with a vascular anomaly were the initial driving force behind my research and likely influenced my interpretation of the participants' experiences. It is also possible that my having a vascular anomaly influenced my interaction with the parents. However, no participants asked about my vascular anomaly, and I chose not to disclose information about my own condition during the research meeting. Additionally, the steps I took to validate the results ensure that my findings are representative of the parents' reports. The rigor of the coding process ensured that the inherent properties of the data guided the development of a conceptual framework. Similarly, the agreement among coders and the validation gained through member checking confirmed that the analyses faithfully represented participants' experiences. Additionally, most grounded theory qualitative scholars would argue that my positionality is not a limitation. In fact, Rubin and Rubin (1995) suggest that trying to assume neutrality in qualitative research is detrimental to the research process. By engaging in reflexivity and disclosing my own subjectivity, I am able to give readers a better understanding of how my experiences and value judgments influence my interpretations.

### **Future Directions**

In addition to the potential avenues for further research suggested above, the results of the study reveal directions for future research exploring parents' uncertainty management and decision making in the context of multidisciplinary care. First, although my goal was to explore uncertainty management and decision making in the context of chronic illness, results of the study also lend support for research guided by Corbin and

Strauss' (1985) concept of chronic illness trajectory. This concept suggests that "illness-related work" is accomplished in times of stability and instability (p. 226). A child's chronic illness may fluctuate between routine and problematic, which can complicate parents' uncertainty management and decision making. For example, parents typically visit a multidisciplinary clinic when their child's illness is problematic. After the visit, their perceptions of the illness may be stable, but at any moment, the illness may become problematic again. Additionally, it is possible that parents' relationships with their pediatricians are affected by their communication with specialists. Parents with young children may face challenges navigating health care with both the team of specialists and their child's pediatrician not only to manage their child's chronic illness, but also to provide routine health care. The evidence of this dynamic illness trajectory highlights the benefit of future research examining parents' uncertainty management and decision making along the illness trajectory, including years after their initial diagnosis and their first visit.

The importance of future research examining parents' experiences across the illness trajectory is also relevant for understanding parents' trust in specialists as credible authorities. Although the findings of the present study confirm Mishel's (1988) position that parents' trust in specialists can result in positive appraisals of uncertainty, it is important to consider that parents' trust may be influenced by a recency effect. Parents may have a high level of trust in the specialists immediately following their visit, but their trust could decrease over time. This dynamic trajectory of trust in providers was demonstrated in one study (Salt, Rayens, Kerr, Alikhan, & Crofford, 2014) that examined rheumatoid arthritis patients' trust over time and found that patients' trust decreased

significantly one week following the clinic visit, especially for less educated patients and patients who consulted the Internet for additional health-related information. These results suggest that future research is needed to examine whether parents' trust in specialists shifts over time and how those changes in trust influence uncertainty management and decision making. Therefore, I could expand the findings of the current study by conducting a longitudinal follow-up study exploring parents' trust in the team of specialists several months after their first visit. Both survey measures and diaries would be useful for understanding the long-term nature of parents' experiences managing pediatric chronic illnesses.

Additionally, the findings lend support for future research more thoroughly exploring the role of social support in the management of uncertainty for parents of children with chronic illnesses. Previous literature suggests that social support is an important aspect of uncertainty experiences (Mishel, 1988; Brashers et al., 2004). The results of the current study suggest that health care providers are an important source of social support for parents of children with vascular anomalies. Their communication with multiple providers can result in support that helps parents manage uncertainty and guide decision making. However, the present investigation did not explore other sources of perceived or enacted social support for parents of children with chronic illnesses. Additional research examining the benefits and challenges of social support beyond the medical consultation would help us gain a better understanding of parents' uncertainty management.

## **Conclusion**

The findings of the current study expand our understanding of parents' uncertainty management and decision making in multidisciplinary care. The results suggest that parents arrive at their first visit with an initial desire to seek information to reduce unwanted uncertainty. However, the results demonstrate that parents are juggling multiple uncertainty management goals when they communicate with specialists. The uncertainty management dilemmas parents face can make them feel overwhelmed and make decision making more difficult. Effective collaboration and mutual agreement between the specialists and parents is an important factor in parents' satisfaction with their decisions. However, I found that autonomy in decision making is not always beneficial. Parents often rely on specialists to guide decision making and reassure them that they are making a good decision for their child. Ultimately, the results confirm that parents' communication with others shapes their appraisals of uncertainty. Their communication with specialists does not necessarily eliminate uncertainty, but rather helps them appraise uncertainty as normal and tolerable. Accepting uncertainty as a normal part of life is an important step in coping with chronic illness.

## Appendix A: Interview Protocol

### Diagnosis:

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1. Can you start by telling me how you first found out about your child's vascular condition?
2. What exactly is your child's diagnosis? (either from before or today's visit)
3. How did you find out about the clinic here at Children's Hospital?
4. What research did you do after finding out about the diagnosis and/or coming here to the clinic? What were your reactions & how did they influence your expectations?

### Multidisciplinary Teams

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5. How many doctors / medical providers did you see today?
6. Can you walk me through the logistics/process of your visit at the clinic from when you arrived until now?
7. Overall, how would you describe the experience of seeing a team of multiple doctors?

### Communication:

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8. How satisfied are you with how the doctors communicated with you today? What was particularly helpful or unhelpful?
9. Did you see the doctors all at once or one at a time?  
How would you describe this process? How did this make you feel?
10. Did the doctors talk in front of you about your child's condition/treatment?  
Example?  
If so, how would you describe this experience? (Pros / Cons)?
11. How would you describe your own communication with the doctors today?  
Example? How satisfied are you with your communication with the doctors today?
12. Can you describe some of the overall benefits of communicating with a team of doctors?
13. Can you describe some of the overall challenges of communicating with a team of doctors? What would you change and/or what complaints would you offer?
14. Was the information you received from the different providers consistent or inconsistent? Example? How did this make you feel?

### Decision-Making:

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15. What types of decisions did you consider during your visit today?
16. Did you make any decisions during your visit today? If so, what was the decision?  
How satisfied are you with that decision? What makes the decision particularly good / bad?
17. What are the alternatives to this decision? What are the risks of the particular options?
18. Decision-making usually involves processing information and building relationships
  - a. How would you describe how the providers helped you process information?

- b. What helped you the most to make sense of the information you needed to make decisions?
  - c. Was there any communication or information that made your decision more difficult or unclear?
  - d. How would you describe the type of relationship the doctors tried to establish with you?
- 19. How knowledgeable do you feel about the information you received today about your child's condition, the treatment, etc.?
- 20. After your visit today, how do you plan to handle future decisions?

Uncertainty:

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- 21. How would you describe any uncertainty (e.g., unanswered questions, ambiguity about care) you have experienced about your child's health care before your visit today? During your visit? Has your level of uncertainty changed during your visit today?
- 22. Uncertainty is often managed with information. What information were you trying to get during your visit with the doctors today? How did you get this information?
- 23. Did the doctors express uncertainty to you about your child's condition, diagnosis, or treatment options? Can you give an example? Can you describe how this made you feel?
- 24. It is not uncommon for people to avoid information that is overwhelming. Was there any information you wanted to avoid during your visit today? How did you avoid this information?
- 25. Can you describe any feelings of uncertainty that are particularly stressful or make you more anxious than others? Any that are particularly helpful or allow you to be more hopeful than others?
- 26. After your visit today, what do you plan to do to handle any feelings of uncertainty?

Final Thoughts

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- 27. Is there anything else you'd like to share before we end the interview?



## Appendix B: Questionnaire

**Before we begin the interview, I am interested in finding out more about you & your child:**

How long have you been seeking care for your child's vascular condition (*i.e.*, birthmark)? \_\_\_\_\_

How many health care providers did you see (*for your child's vascular condition / birthmark*) before your visit today? \_\_\_\_\_

What is your child's (*the patient's*) age? \_\_\_\_\_ What is your child's sex? \_\_\_\_\_

Please list your child's primary diagnosis (*if it is known*): \_\_\_\_\_

(*If applicable*) When did you receive this diagnosis (*month/year*)? \_\_\_\_\_

From whom did you receive this diagnosis? \_\_\_\_\_

**It is possible you discussed many decisions during your visit today. For the next set of items, think back to the most important decision you discussed with the health care providers (*e.g.*, *doing treatment, waiting to do treatment, compression garment, pain control, etc.*).**

**On a scale of 1 to 7, indicate how much each statement is true for you at this time by writing the corresponding number on the blank provided next to each statement.**

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Do Not Agree or Disagree	Slightly Agree	Agree	Strongly Agree

- \_\_\_\_\_1. I am satisfied that I am adequately informed about the issues important to my decisions.
- \_\_\_\_\_2. The decisions I made were the best possible decisions for me personally.
- \_\_\_\_\_3. I am satisfied that my decisions were consistent with my personal values.
- \_\_\_\_\_4. I expect to successfully carry out (or continue to carry out) the decisions I made.
- \_\_\_\_\_5. I am satisfied that these were my decisions to make.
- \_\_\_\_\_6. I am satisfied with my decisions.
- \_\_\_\_\_7. These decisions will be hard to make.
- \_\_\_\_\_8. I'm unsure what to do in these decisions.
- \_\_\_\_\_9. It's clear what choices will be best for me.
- \_\_\_\_\_10. These decisions will be made without me.
- \_\_\_\_\_11. I feel pressure from others in making these decisions.
- \_\_\_\_\_12. I wish someone else would decide for me.
- \_\_\_\_\_13. I am satisfied with the information I have about these choices.
- \_\_\_\_\_14. I know the pros and cons of treatment.
- \_\_\_\_\_15. I want more information about these decisions.
- \_\_\_\_\_16. I want clearer advice.

**Overall, on a scale of 1 to 7, how satisfied were you with your visit to the clinic today?**

*Unsatisfied*      1              2              3              4              5              6              7              *Satisfied*

**Lastly, I would like to find out a little more information about you:**

What is your current age? \_\_\_\_\_

Where do you currently live (city/state)? \_\_\_\_\_

What is your sex?

- ☐ Male
- ☐ Female
- ☐ *Choose not to answer*

What is your racial/ethnic background (*select all that apply*)?

- ☐ American Indian/Alaskan Native
- ☐ Asian
- ☐ Black/African American
- ☐ Hispanic/Latino
- ☐ Native Hawaiian/Pacific Islander
- ☐ White/Caucasian
- ☐ Other: \_\_\_\_\_
- ☐ *Choose not to answer*

What is your current relationship status (*select one*)?

- ☐ Single, never married
- ☐ Serious relationship
- ☐ Married
- ☐ Separated
- ☐ Divorced
- ☐ Widowed/Widower

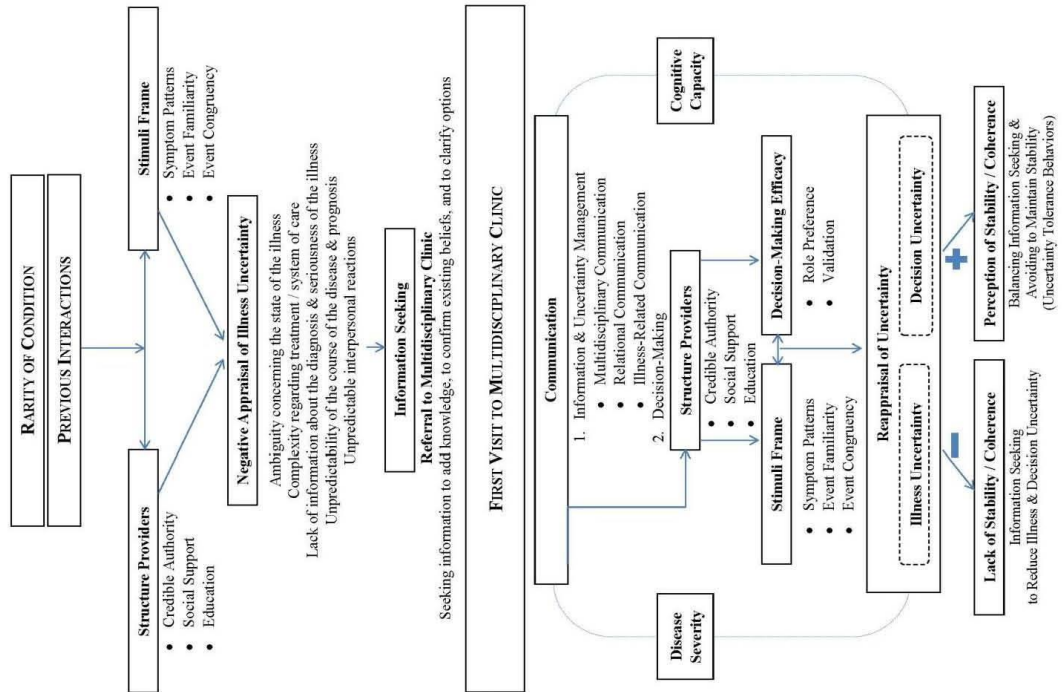
What is the highest level of education you have completed (*select one*)?

- ☐ Some high school
- ☐ High school degree / GED
- ☐ Some college
- ☐ 2-year degree (Associate Degree)
- ☐ 4-year degree (Bachelor's Degree)
- ☐ Master's Degree
- ☐ Doctoral Degree
- ☐ Professional Degree (M.D., J.D.)

What is your average yearly household income (*select one*)?

- ☐ Below \$20,000
- ☐ \$20,000 - \$39,999
- ☐ \$40,000 - \$59,999
- ☐ \$60,000 - \$79,999
- ☐ \$80,000 - \$99,999
- ☐ \$100,000 or above
- ☐ *Choose not to answer*

## PARENTS' UNCERTAINTY & DECISION-MAKING DURING THEIR FIRST VISIT TO A MULTIDISCIPLINARY CLINIC



1. Parents' experiences before coming to the multidisciplinary clinic contributed to their uncertainty about their child's condition. When parents' did not feel as though their doctor was an expert in this area, received conflicting information about the condition, or had unsupportive interactions with others, they experienced uncertainty about their child's health care. Because parents wanted to reduce their uncertainty, they engaged in information seeking by obtaining a referral to a multidisciplinary clinic at Cincinnati Children's Hospital.
2. Parents wanted to seek as much information as possible during their visit to Cincinnati Children's Hospital Hemangioma and Vascular Malformation Clinic in order to expand their knowledge, confirm/reject what they had heard previously, or to find out options for treatment/management of the condition.
3. During parents' visit to the multidisciplinary hemangioma and vascular malformation clinic, four primary elements of the visit affected parents' uncertainty about the illness and the decision(s) to be made:
  - a. If the doctors were friendly, approachable, and reassuring
  - b. If the doctors seemed intelligent and provided good explanations,
  - c. If the parents received multiple opinions from experts in the field
  - d. If the parents were satisfied with the decision-making process and felt validated in their decision and the role they played in making a decision
4. After the visit, parents tended to reevaluate their uncertainty about the illness and the decisions they may need to make in the future:
  - a. When the communication climate was positive, parents reappraised uncertainty as something that is not a negative experience. Parents did not necessarily *eliminate* uncertainty, but were able to *tolerate* uncertainty and learn how to create stability in their (and their child's) lives moving forward. Parents were satisfied with the decision(s) made and often embraced the "wait and see" approach as a positive decision and learned to balance information-seeking and information-avoiding (i.e., waiting to discuss alternative options in the future) to create stability in their lives.
  - b. When the communication climate was less positive, parents reappraised their uncertainty as a negative feeling. This often resulted in a strong desire to seek more information to reduce both uncertainty about the illness and uncertainty about the decisions discussed during the visit. These parents showed less tolerance for uncertainty moving forward and were not necessarily satisfied with the decision(s) made during the visit. If a "wait and see" decision was made it was often to continue to do more information seeking before making any decisions.

## Appendix D: Member Checking Validation

1. I think your conceptual map is absolutely on target. The uncertainty is frightening. In going through the steps with Cincinnati Children's Hospital, it was reassuring to know that a team of professionals were not concerned about my daughter's hemangioma. While they gave us a "wait and see" as outlined on your map, it was with an extremely positive outlook and almost no anticipation of further issues. This helped both me and my wife to feel secure in knowing that a team of professionals not only were upbeat but nonplussed by her growth.
2. You ask
  1. Do you believe this summary accurately describes the communication, uncertainty, and decision-making experiences you had at the Cincinnati Children's Hospital Hemangioma & Vascular Malformation Center?
  2. If your answer to the question above was NO, what element(s) of the results do not match your experiences? What would you add or remove?

The answer to number 1 would be YES. I believe the chart expertly dictates the communication--decision making experience/process

3. I have looked over your document and feel that it accurately represented my experience at the center. I am only able to comment with certainty on the positive points on your concept map as those represent my feelings.
4. I believe that this summary accurately describes the communication, uncertainty, and decision making experience very well.

I strongly relate to #2 and #3D.

The only other piece that I would say was not addressed is that most parents/people have had little or no experience with this diagnosis prior to this experience with their child. The uncertainty is not just related to those items in #1 but to our own limited knowledge and feeling unprepared. If the diagnosis was something else, we would have a better frame of reference.

5. Answers to your questions:
  - 1) Absolutely. If given weeks or months, I am not sure I could have summed up my feelings, emotions, and/or thoughts in a more concise manner.
  - 2) I feel it comes at the problem and solution from multiple angles and encompasses the entire experience very accurately.
6. Yes, this very accurately describes our experience. I especially like the statement "parents did not necessarily eliminate uncertainty, but were able to tolerate it." That is definitely where we are.

## References

- Alvesson, M., & Skoldberg, K. (2009). *Reflexive methodology: New vistas for qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
- Babrow, A. S. (2001). Uncertainty, value, communication, and problematic integration. *Journal of Communication*, 51, 553-573. doi: 10.1111/j.1460-2466.2001.tb02896.x
- Babrow, A. S., Kasch, C. R., & Ford, L. A. (1998). The many meanings of uncertainty in illness: Toward a systematic accounting. *Health Communication*, 10, 1-23. doi: 10.1207/s15327027hc1001\_1
- Babrow, A. S., & Kline, K. N. (2000). From "reducing" to "coping with" uncertainty: Reconceptualizing the central challenge in breast self-exams. *Social Science and Medicine*, 51, 1805-1816. doi: 10.1016/S0277-9536(00)00112-X
- Barbour, J. B., Rintamaki, L. S., Ramsey, J. A., & Brashers, D. E. (2012). Avoiding health information. *Journal of Health Communication*, 17, 212-229. doi: 10.1080/10810730.2011.585691
- Bearison, D. J., Sadow, A. J., Granowetter, L., & Winkel, G. (1993). Patients' and parents' causal attributions for childhood cancer. *Journal of Psychosocial Oncology*, 11, 47-61. doi: 10.1300/J077V11N03\_03
- Beauchamp, T. L., & Childress, J. F. (2001). *Principles of biomedical ethics*. New York: Oxford University Press.
- Berger, C. R., & Calabrese, R. (1975). Some explorations in initial interactions and beyond: Toward a developmental theory of interpersonal communication. *Human Communication Research*, 1, 99-112. doi: 10.1111/j.1468-2958.1975.tb00258.x
- Bethell, C. D., Read, D., Blumberg, S. J., & Newacheck, P. W. (2008). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal*, 12, 1-14. doi: 10.1007/s10995-007-0220-5
- Boyd, E. A., Lo, B., Evans, L. R., Malvar, G., Apatira, L., Luce, J. M., & White, D. B. (2010). "It's not just what the doctor tells me:" Factors that influence surrogate decision-makers' perceptions of prognosis. *Critical Care Medicine*, 38, 1270-1275. doi: 10.1097/CCM.0b013e3181d8a217
- Braddock, C. H., Edwards, K. A., Hasenberg, N. M., Laidley, T. L., & Levinson, W. (1999). Informed decision making in outpatient practice: Time to get back to basics. *Journal of the American Medical Association*, 282, 2313-2320. doi: 10.1001/jama.282.24.2313
- Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication*, 51, 477-497. doi: 10.1111/j.1460-2466.2001.tb02892.x
- Brashers, D. E., & Babrow, A. S. (1996). Theorizing communication and health. *Communication Studies*, 47, 243-251. doi: 10.1080/10510979609368479
- Brashers, D. E., Neidig, J. L., Cardillo, L. W., Dobbs, L. K., Russell, J. A., & Haas, S. M. (1999). 'In an important way, I did die.' Uncertainty and revival among persons living with HIV or AIDS. *AIDS Care*, 11, 201-219. doi: 10.1080/09540129948090

- Brashers, D. E., Neidig, J. L., Goldsmith, D. J. (2004). Social support and the management of uncertainty for people living with HIV or AIDS. *Health Communication, 16*, 305-331. doi: 10.1207/S15327027HC1603\_3
- Brashers, D. E., Neidig, J. L., Haas, S. M., Dobbs, L. K., Cardillo, L. W., & Russell, J. A. (2000). Communication in the management of uncertainty: The case of persons living with HIV or AIDS. *Communication Monographs, 67*, 63-84. doi: 10.1080/03637750009376495
- Brashers, D. E., Neidig, J. L., Reynolds, N. R., & Haas, S. M. (1998). Uncertainty in illness across the HIV/AIDS trajectory. *Journal of the Association of Nurses in AIDS Care, 9*, 66-77. doi: 10.1016/S1055-3290(98)80078-2
- Brashers, D. E., Neidig, J. L., Russell, J. A., Cardillo, L. W., Haas, S. M., Dobbs, L. K., . . . Nemeth, S. (2003). The medical, personal, and social causes of uncertainty in HIV illness. *Issues in Mental Health Nursing, 24*, 497-522. doi: 10.1080/01612840305292
- Buckmiller, L. M., Richter, G. T., & Suen, J. Y. (2010). Diagnosis and management of hemangiomas and vascular malformations of the head and neck. *Oral Diseases, 16*, 405-418. doi: 10.1111/j.1601-0825.2010.01661.x
- Burrows, P. E., Tal Laor, H. P., & Robertson, R. L. (1998). Diagnostic imaging in the evaluation of vascular birthmarks. *Dermatologic Clinics, 16*, 455-488. doi: 10.1016/S0733-8635(05)70246-1
- Centers for Disease Control and Prevention. (2011). *Birth defects: Data and statistics*. Retrieved from <http://www.cdc.gov/NCBDDD/birthdefects/data.html>
- Cegala, D. J., McNeilis, K. S., McGee, D. S., & Jonas, A. P. (1995). A study of physicians' and patients' perceptions of information processing and communication competence during the medical interview. *Health Communication, 7*, 179-203. doi: 10.1207/s15327027hc0703\_1
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed., pp. 509-536). Thousand Oaks, CA: Sage.
- Cherlin, E., Fried, T., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, R., & Bradley, E. H. (2005). Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *Journal of Palliative Medicine, 8*, 1176-1185. doi: 10.1089/jpm.2005.8.1176
- Clarke, J. N., & Fletcher, P. (2005). Parents as advocates. *Social Work in Health Care, 39*, 107-127. doi: 10.1300/J010v39n01\_08
- Clarke-Steffen, L. (1993). Waiting and not knowing: The diagnosis of cancer in a child. *Journal of Pediatric Oncology Nursing, 10*, 146-153. doi: 10.1177/104345429301000405
- Clarke-Steffen, L. (1997). Reconstructing reality: Family strategies for managing childhood cancer. *Journal of Pediatric Nursing, 12*, 278-287. doi: 10.1016/S0882-5963(97)80045-0
- Cohen, M. H. (1993a). Diagnostic closure and the spread of uncertainty. *Issues in Comprehensive Pediatric Nursing, 16*, 135-146. doi: 10.3109/01460869309078270

- Cohen, M. H. (1993b). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research*, 15, 77-96. doi: 10.1177/019394599301500106
- Cohen, M. H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. *Qualitative Health Research*, 5, 63-77. doi: 10.1177/104973239500500105
- Committee on Bioethics. (1995). American Academy of Pediatrics: Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*, 95, 314-317. Retrieved from <http://www.nocirc.org/consent/bioethics.php>.
- Cooley, E. (1994). Training an interdisciplinary team in communication and decision-making skills. *Small Group Research*, 25, 5-25. doi: 10.1177/1046496494251002
- Corbin, J., & Strauss, A. (1985). Managing chronic illness at home: Three lines of work. *Qualitative Sociology*, 8, 224-247. doi: 10.1007/BF00989485
- Corbin, J., & Strauss, A. L. (1987). Accompaniments of chronic illness: Changes in body, self, biography, and biographical time. *Research in the Sociology of Health Care*, 6, 249-281.
- Corbin, J. M., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.) Thousand Oaks, CA: Sage.
- Cott, C. (1998). Structure and meaning in multidisciplinary teamwork. *Sociology of Health and Illness*, 20, 848-873. doi: 10.1111/1467-9566.00132
- Curtis, J. R., Patrick, D., Shannon, S., Treece, P., Engelberg, R., & Rubenfeld, G. (2001). The family conference as a focus to improve communication about end-of-life care in the intensive care unit: Opportunities for improvement. *Critical Care Medicine*, 26, N26-N33. doi: 10.1097/00003246-200102001-00006
- Donnelly, L. F., Adams, D. M., & Bisset, G. S. (2000). Vascular malformations and hemangiomas: A practical approach in a multidisciplinary clinic. *American Journal of Roentgenology*, 174, 597-608. doi: 10.2214/ajr.174.3.1740597
- Ellingson, L. L. (2008). Interdisciplinary health care: Teamwork in the clinic backstage. In L. C. Lederman (Ed.), *Beyond these walls: Readings in health communication* (pp. 183-203). New York: Oxford University Press.
- Emanuel, E. J., & Emanuel, L. L. (1992). Proxy decision making for incompetent patients: An ethical and empirical analysis. *Journal of the American Medical Association*, 267, 2067-2071. doi: 10.1001/jama.1992.03480150073040
- Enjolras, O., Wassef, M., & Chapot, R. (2007). *Color atlas of vascular tumors and vascular malformations*. New York: Cambridge University Press.
- Epstein, R. M., & Street, R. L. (2011). Shared mind: Communication, decision making, and autonomy in serious illness. *Annals of Family Medicine*, 9, 454-461. doi: 10.1370/afm.1301
- Fiorelli, J. S. (1988). Power in work groups: Team member's perspectives. *Human Relations*, 41, 1-12. doi: 10.1177/001872678804100101
- Fontana, A., & Frey, J. H. (2000). The interview: From structured questions to negotiated text. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 645-672). Thousand Oaks, CA: Sage.
- Forrest, C. B., Majeed, A., Weiner, J. P., Carroll, K., & Bindman, A. (2003). Referral of children to specialists in the United States and the United Kingdom. *Pediatrics and Adolescent Medicine*, 157, 279-285. doi: 10.1001/archpedi.157.3.279

- Frey, L. R., Botan, C. H., & Kreps, G. L. (Eds.). (2000). *Investigating communication: An introduction to research methods* (2nd ed.). Boston: Allyn and Bacon.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Graugaard, P. K., Holdersen, K., Eide, H., & Finset, A. (2005). Changes in physician-patient communication from initial to return visits: A prospective study in a haematology outpatient clinic. *Patient Education and Counseling*, 57, 22-29. doi: 10.1016/j.pec.2004.03.014
- Groves, R. M., Fowler, F. J., Couper, M. P., Lepkowski, J. M., Singer, E., & Tourangeau, R. (Eds.). (2009). *Survey methodology* (2nd ed.). Hoboken, NJ: John Wiley and Sons.
- Gudykunst, W. B. (1995a). Theorizing in intercultural communication. In R. L. Wiseman (Ed.), *Intercultural communication theory* (pp. 8-58). Thousand Oaks, CA: Sage.
- Gudykunst, W. B. (1995b). The uncertainty reduction and anxiety-reduction theories of Berger, Gudykunst, and associates. In D. P. Cushman & B. Kovacic (Eds.), *Watershed research traditions in human communication theory* (pp. 67-100). Albany, NY: State University of New York Press.
- Halfon, N., & Newacheck, P. W. (2010). Evolving notions of childhood chronic illness. *Journal of the American Medical Association*, 303, 665-666. doi: 10.1001/jama.2010.130
- Hassanein, A. H., Mulliken, J. B., Fishman, S. J., & Greene, A. K. (2011). Evaluation of terminology for vascular anomalies in current literature. *Plastic Reconstructive Surgery*, 127, 347-351. doi: 10.1097/PRS.0b013e3181f95b83
- Henry, M. S. (2006). Uncertainty, responsibility, and the evolution of the physician/patient relationship. *Journal of Medical Ethics*, 32, 321-323. doi: 10.1136/jme.2005.013987
- Hesse, B. W., Nelson, D. E., Kreps, G. L., Croyle, R. T., Arora, N. K., Rimer, B. K., Viswanath, K. (2005). Trust and sources of health information: The impact of the Internet and its implications for health care providers: Findings from the first Health Information National Trends survey. *Archives of Internal Medicine*, 165(22), 2618-2624. doi: 10.1001/archinte.165.22.2618
- Hinds, P. S., Birenbaum, L. K., Clarke-Steffen, L., Quargnenti, A., Kreissman, S., Kazak, A., . . . Williams, J. (1996). Coming to terms: Parents' response to a first cancer recurrence in their child. *Nursing Research*, 45, 148-153. doi: 10.1097/00006199-199605000-00005
- Hinds, P. S., & Kelly, K. P. (2010). Helping parents make and survive end of life decisions for their seriously ill child. *Nursing Clinics of North America*, 45, 465-474. doi: 10.1016/j.cnur.2010.03.006
- Hinds, P. S., Oakes, L., Furman, W., Foppiano, P., Olson, M. S., Quargnenti, A., . . . Strong, C. (1997). Decision making by parents and healthcare professionals when considering continued care for pediatric patients with cancer. *Oncology Nursing Forum*, 24, 1523-1528.
- Hinds, P. S., Oakes, L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., . . . Furman, W. L. (2009). "Trying to be a good parent" as defined by interviews with parents who make phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27, 5979-5985. doi: 10.1200/JCO.2008.20.0204



- Holmes-Rovner, M., Kroll, J., Schmitt, N., Rovner, D. R., Breer, M. L., Rothert, M. L., ... Talarczyk, G. (1996). Patient satisfaction with health care decisions: The satisfaction with decision scale. *Medical Decision Making*, 16, 56-64. doi: 10.1177/0272989X9601600114
- Kahneman, D. & Tversky, A. (1981). The framing of decisions and the psychology of choice. *Science*, 211, 453-458. doi: 10.1126/science.7455683
- Kassirer, J. P. (1994). Incorporating patients' preferences into medical decisions. *New England Journal of Medicine*, 30, 1895-1896. doi: 10.1056/NEJM199406303302611
- Katz, J. (1984). Why doctors don't disclose uncertainty. *The Hastings Center Report*, 14, 35-44. doi: 10.2307/3560848
- Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing*, 11, 315-326. doi: 10.1016/S0882-5963(05)80065-X
- Lamb, B. W., Taylor, C., Lamb, J. N., Strickland, S. L., Vincent, C., Green, J. S. A., & Sevdalis, N. (2013). Facilitators and barriers to teamworking and patient centeredness in multidisciplinary cancer teams: Findings of a national study. *Annals of Surgical Oncology*, 20, 1408-14016. doi: 10.1245/s10434-012-2676-9
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, & coping*. New York: Springer.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Makary, M. A. (2011). Multidisciplinary teams and clinics: Better care or just more care? *Annals of Surgical Oncology*, 18, 2105-2106. doi: 10.1245/s10434-011-1678-3
- Mathes, E. F. D., Haggstrom, A. N., Dowd, C., Hoffman, W. Y., & Frieden, I. (2004). Clinical characteristics and management of vascular anomalies: Findings of a multidisciplinary clinic. *Archives of Dermatology*, 140, 979-983. doi: 10.1001/archderm.140.8.979
- McCormick, K. M. (2002). A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship*, 34, 127-131. doi: 10.1111/j.1547-5069.2002.00127.x
- Mickan, S. M., & Rodger, S. A. (2005). Effective health care teams: A model of six characteristics developed from shared perceptions. *Journal of Interprofessional Care*, 19, 358-370. doi: 10.1080/13561820500165142
- Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research*, 30, 258-263. doi: 10.1097/00006199-198109000-00002
- Mishel, M. H. (1988). Uncertainty in illness. *Image: Journal of Nursing Scholarship*, 20, 225-232. doi: 10.1111/j.1547-5069.1988.tb00082.x
- Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: Journal of Nursing Scholarship*, 22, 256-262. doi: 10.1111/j.1547-5069.1990.tb00225.x
- Mishel, M. H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, 17, 269-294.
- Mishel, M. H., & Braden, C. J. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research*, 37, 98-103. doi: 10.1097/00006199-198803000-00009
- O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making*, 15, 25-30. doi: 10.1177/0272989X9501500105

- Patel, R. V., & Curry, J. I. (2010). Vascular malformations. In C. K. Sinha & M. Davenport (Eds.), *Handbook of pediatric surgery* (pp. 213-227). London: Springer.
- Patient Self Determination Act of 1990, 42 U.S.C. § 1395 et seq. (1991).
- Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association*, 297, 2755-2759. doi: 10.1001/jama.297.24.2755
- Politi, M. C., Han, P. K., & Col, N. F. (2007). Communicating the uncertainty of harms and benefits of medical interventions. *Medical Decision Making*, 27, 681-695. doi: 10.1177/0272989X07307270
- Politi, M. C., & Street, R. L., Jr. (2011). The importance of communication in collaborative decision making: Facilitating shared mind and the management of uncertainty. *Journal of Evaluation in Clinical Practice*, 17, 579-584. doi: 10.1111/j.1365-2753.2010.01549.x
- Poole, M. S., & Real, K. (2003). Groups and teams in health care: Communication and effectiveness. In T. L. Thompson, A. M. Dorsey, K. I. Miller, & R. Parrott (Eds.), *Handbook of Health Communication* (pp. 369-402). Mahwah, N.J.: Lawrence Erlbaum Publishers.
- Quill, T. E., & Suchman, A. L. (1993). Uncertainty and control: Learning to live with medicine's limitations. *Humane Medicine*, 9. Retrieved from Humane Medicine website: [http://www.humanehealthcare.com/Article.asp?art\\_id=440](http://www.humanehealthcare.com/Article.asp?art_id=440)
- Real, K., & Poole, M. S. (2011). Health care teams: Communication and effectiveness. In T. L. Thompson, R. Parrott, & J. Nussbaum (Eds.) *Handbook of Health Communication*, 2nd Ed. (pp. 100-116). New York: Routledge.
- Richter, G. T., & Friedman, A. B. (2012). Hemangiomas and vascular malformations: Current theory and management. *International Journal of Pediatrics*, 2012, 1-10. doi: 10.1155/2012/645678
- Rieu, P. N. M. A., & Festen, C. (1996). Hemangioma and vascular malformations. *Pediatric Surgery International*, 11, 289-289. doi: 10.1007/BF00497794
- Rimer, B. K., Briss, P. A., Zeller, P. K., Chan, E. C. Y., & Woolf, S. H. (2004). Informed decision-making: What is its role in cancer screening? *Cancer*, 101, 1214-1228. doi: 10.1002/cncr.20512
- Roter, D. L., Hall, J. A., & Aoki, Y. (2002). Physician gender effects in medical communication: A meta-analytic review. *Journal of the American Medical Association*, 288, 756-764. doi: 10.1001/jama.288.6.756af
- Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Scott, A. M., Martin, S. C., Stone, A. M., & Brashers, D. E. (2011). Managing multiple goals in supportive interactions: Using a normative, theoretical approach to explain social support as uncertainty management for organ transplant patients. *Health Communication*, 26, 393-403. doi: 10.1080/10410236.2011.552479
- Salt, E., Rayens, M.K., Kerr, A.M., Alikhan, M., Crofford, L.J. (2014). *Examining rheumatoid arthritis patients' trust in their provider over time: The effects of demographic factors and accessing sources of information*. Manuscript submitted for publication.

- Sharman, M., Meert, K., & Sarnaik, A. P. (2005). What influences parents' decisions to limit or withdraw life support? *Pediatric Critical Care Medicine*, 6, 513-518. doi: 10.1097/01.PCC.0000170616.28175.D9
- Shaw, A., De Lusignan, S., & Rowlands, G. (2005). Do primary care professionals work as a team: A qualitative study. *Journal of Interprofessional Care*, 19, 396-405. doi: 10.1080/13561820500053454
- Siegl, D., & Morse, J. M. (1994). Tolerating reality: The experience of parents of HIV positive sons. *Social Science and Medicine*, 38, 959-971. doi: 10.1016/0277-9536(94)90428-6
- Siminoff, L. A., & Step, M. M. (2005). A communication model of shared decision making: Accounting for cancer treatment decisions. *Health Psychology*, 24, S99-S105. doi: 10.1037/0278-6133.24.4.S99
- Stille, C. J., McLaughlin, T. J., Primach, W. A., Mazor, K. M., & Wasserman, R. C. (2006). Determinants and impact of generalist-specific communication about pediatric outpatient referrals. *Pediatrics*, 118, 1341-1349. doi: 10.1542/peds.2005-3010
- Stalmeier, P. F. M., Roosmalen, M. S., Verhoef, L. C. G., Hoekstra-Weebers, J. E. H. M., Oosterwijk, J. C., Moog, U., ... van Daal, W. A. J. (2005). The decision evaluation scales. *Patient Education and Counseling*, 57, 286-293. doi: 10.1016/j.pec.2004.07.010
- Step, M. M., & Ray, E. B. (2011). Patient perceptions of oncologist-patient communication about prognosis: Changes from initial diagnosis to cancer recurrence. *Health Communication*, 26, 48-58. doi: 10.1080/10410236.2011.527621
- Stewart, J. L., & Mishel, M. H. (2000). Uncertainty in childhood illness: A synthesis of the parent and child literature. *Scholarly Inquiry for Nursing Practice*, 14, 299-319.
- Street, R. L. (1992). Communicative styles and adaptations in physician-parent consultations. *Social Science & Medicine*, 34, 1155-1163. doi: 10.1016/0277-9536(92)90289-3
- Torke, A. M., Petronio, S., Sachs, G. A., Helft, P. R., & Purnell, C. (2012). A conceptual model of the role of communication in surrogate decision making for hospitalized adults. *Patient Education and Counseling*, 87, 54-61. doi: 10.1016/j.pec.2011.07.027
- Turner, M. A., Tomlinson, P. S., & Harbaugh, B. L. (1990). Parental uncertainty in critical care hospitalization of children. *Maternal-Child Nursing Journal*, 19, 45-62.
- Vascular Birthmark Foundation. (2011). *Birthmarks*. Retrieved from [www.birthmark.org](http://www.birthmark.org).
- Wagner, E. H. (2000). The role of patient care teams in chronic disease management. *British Medical Journal*, 320, 569-572. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1117605/>
- Watzlawick, P., Beavin, J. B., & Jackson, D. D. (1967). *Pragmatics of human communication*. New York: Norton.
- Whitney, S. N., McGuire, A. L., & McCullough, L. B. (2004). A typology of shared decision making, informed consent, and simple consent. *Annals of Internal Medicine*, 140, 54-59. doi: 10.7326/0003-4819-140-1-200401060-00012

**Anna M. Kerr**  
**Vita**

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**Education**

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|-------------|---------------------------------|--------------------------------------|
| <b>2010</b> | <b>University of Cincinnati</b> | Master of Arts in Communication      |
| <b>2008</b> | <b>Ohio University</b>          | Bachelor of Science in Communication |

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**Professional Experience**

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**Research Assistant - A Model of Decision-Making in Rheumatoid Arthritis**

University of Kentucky, College of Nursing (June, 2011 – Present)

**Research Assistant - ACTIVE Intervention to Improve Hospice Caregiver Pain Management**

University of Kentucky, Department of Communication (July, 2011 – February, 2012)

**Research Assistant - An Intervention for Promoting Smoke-free Policy in Rural Kentucky**

University of Kentucky, Center for Smoke-Free Policy (April, 2011 – August, 2011)

**Graduate Teaching Assistant – Instructor of Record**

University of Kentucky, College of Communication and Information (August, 2010 – May, 2013)

**Graduate Teaching Assistant – Instructor of Record**

University of Cincinnati, College of Arts and Sciences (September, 2008 – June, 2010)

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**Professional & Scholastic Honors**

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- Dissertation Enhancement Award, University of Kentucky (April, 2013)
- Student Research Presentation of Distinction Award, DC Area Health Communication Conference (March, 2013)
- Nominee for the National and International Communication Association Outstanding Thesis in Health Communication (January, 2011)
- R. Lewis Donohew Health Communication Fellowship, University of Kentucky (2010 – 2011)

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**Peer-Reviewed Publications**

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Salt, E., Rayens, M.K., **Kerr, A.M.**, Alikhan, M., Crofford, L.J. (2014). *Examining rheumatoid arthritis patients' trust in their provider over time: The effects of demographic factors and accessing sources of information*. Manuscript submitted for publication.

**Kerr, A. M.**, & Haas, S. M. (in press). Parental uncertainty in illness: Managing uncertainty surrounding an 'orphan' illness. *Journal of Pediatric Nursing*.

Wittenberg-Lyles, E., Goldsmith, J., Parker Oliver, D., Demiris, G., **Rankin, A. M.** (2012). Targeting communication interventions to decrease oncology family caregiver burden. *Seminars in Oncology Nursing - Family Caregivers Issue*, 28, 262-270. doi: 10.1016/j.soncn.2012.09.009 (PMCID3143374)

Wittenberg-Lyles, E., Parker Oliver, D., Demir, G., **Rankin, A.**, Shaunfield, S., & Kruse, R. (2012). Conveying empathy to hospice family caregivers: Team responses to caregiver empathic communication. *Patient Education and Counseling*, 89, 31-17. doi: 10.1016/j.pec.2012.04.004 (PMCID: NIHMSID369310)

### **Invited Publications**

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**Kerr, A. M.** (Forthcoming). Surrogate decision makers. *SAGE Encyclopedia of Health Communication*.

Scott, A. M., & **Kerr, A. M.** (Forthcoming). Communication with families. *SAGE Encyclopedia of Health Communication*.

**Rankin, A.M.** (Forthcoming). Internet identity theft: Self-protection steps [Sample Speech]. In R. F. Verderber, *The Challenge of Effective Speaking in a Digital Age*, (16<sup>th</sup> ed.). Plymouth, MA: Cengage.